ALZHEIMER'S DISEASE AND RELATED DISORDERS: THE GOVERNMENT'S RESPONSE

HEARING

BEFORE THE

SELECT COMMITTEE ON AGING
HOUSE OF REPRESENTATIVES

NINETY-NINTH CONGRESS

SECOND SESSION

JUNE 21, 1986, COLD SPRING HARBOR, NY

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ALZHEIMER'S DISEASE AND RELATED DISORDERS: THE GOVERNMENT'S RESPONSE

SATURDAY, JUNE 21, 1986

HOUSE OF REPRESENTATIVES,
SELECT COMMITTEE ON AGING,
Cold Spring Harbor, NY.

The committee met, pursuant to notice, at 1:15 p.m., at Grace Auditorium, Cold Spring Harbor Laboratory, Cold Spring Harbor, NY, Hon. Thomas J. Downey (acting chairman of the committee) presiding.

Members present: Representatives Downey, Manton, and Mrazek.

OPENING STATEMENT OF REPRESENTATIVE THOMAS J. DOWNEY

Mr. DOWNEY. I call the hearing to order.

Because we are with Long Islanders and friends, you may not be familiar with the way a hearing of the House of Representatives is conducted. I will try and explain how this works and how it will work so that we can proceed in an orderly manner and not appear to be indifferent or unconcerned.

The hearing is held under the auspices of the Committee on the Aging, and I am chairing it in that capacity. Congressman Mrazek and I will listen to the testimony of witnesses which has been prepared in advance. The witnesses will make statements of 5 minutes or under. If it runs over 5 minutes, I will gavel them out of order and the rest of their statement will be submitted for the record.

There are lots of people who have to testify today and lots of testimony we have to receive. This is not done because we are rude. We are not. It is just because we want to get on with the business.

Bob and I will ask the questions. We are receiving the testimony. You may feel compelled from time to time, if you hear something you agree strongly with or disagree to just jump up and say so. When you do, I will hit the gavel and ask you, likely, to be seated.

There will be an opportunity for those of you who, after listening to the witnesses and wanting to make statements, to submit those statements in writing to either our office in West Islip or to Bob's office here in Huntington. We will make your statement part of the hearing record.

Because of time constraints, I will be departing this hearing at about 2:15. Congressman Manton will be here and at that time Congress Mrazek will conduct the rest of the hearing.

I want to begin by complimenting Bob for requesting and arranging this hearing. The problems of Alzheimer's disease and related

disorders in terms of our Government's response and the human suffering involved deserves our attention. It is much to his credit that Bob recognizes this and that the Select Committee on Aging is looking into it.

The figures are all too familiar to most of us in this room; 1.5 million nursing home patients in this country, an estimated 50 percent, suffer from Alzheimer's. More than $20 billion is spent every year on care for Alzheimer's victims and as our population grows older many more of our citizens will find themselves in the abyss that is Alzheimer's disease.

When and how will the Federal Government will come to grips with this situation?

Thanks to the efforts of the chairman of the Select Committee on Aging, Mr. Roybal, and other colleagues of mine in the House and Senate, we have seen some progress. Federal support for Alzheimer's research, while we fall short of what is necessary, has grown in the last 5 years. Support groups for families of Alzheimer's victims have grown exponentially. But there is, and as our witnesses here will so testify, substantially more that must be done. Estimates tell us that the cost of caring for Alzheimer's victims runs from $30,000 to $50,000 per year. Much of this care is not paid for either by private insurance companies or the Medicare Program.

The long-term custodial care that is necessary for Alzheimer's victims most often falls right on the backs of their families. How can a husband or wife of an Alzheimer's victim earn a living and devote the necessary time to caring for the patient? Without vast resources it is obviously very, very difficult, if not impossible.

How does one deal with the emotional strain caused by caring for one's loved one who is being reduced to a shell of his or her former self? The victims of Alzheimer's are the families of the affected persons. Certainly, those families who have been victimized by Alzheimer's provide the lion's share of the care that is required if only because there is no one else to do it.

We all must compliment the extraordinary patience and care that such care and caring requires. There are many documented cases of 55- to 60-year-old children caring for parents with Alzheimer's, while also providing help to their own children and grandchildren. While we can marvel at the will and determination it takes for such people to provide such loving care, we must be able to do more than marvel. We must help them.

Today we will examine many of the questions surrounding Alzheimer's disease, the treatment, funding for research, legal aspects, and support for families of Alzheimer's victims, all part of the broad agenda of this particular hearing. And I look forward to hearing the testimony of our expert witnesses and reporting the results back to my colleagues in the House.

Bob, I want to congratulate you. Please proceed with your opening statement.

STATEMENT OF REPRESENTATIVE ROBERT J. MRAZEK

Mr. MRAZEK. Thank you, Tom.

I would like to thank you and Tom Manton—I am not Tom Manton—for giving this hearing the official requirement it needs

to have a hearing record which will be presented to every Member of Congress on this very important issue.

I have a formal statement I would like to submit for the record.

I would also, in particular, like to thank Dave Miklos, the public affairs director for the labs, for providing this comfortable and convenient backdrop for this important hearing. I am reminded of the fact that I used to work here, as a matter of fact, at the labs, and in a small way I like to feel I had a contribution to make in the winning of several Nobel Prizes here at the lab. I used to work on the ground crew here during the summers and I sort of feel that as Barbara Maclintok was earning her Nobel Prize here at the lab, seeing that carefully mown grass I provided to her gave her the mental calmness to do the important work she did.

I would also particularly like to thank Susan Scheier of my office, who really did a tremendous amount of work in making this hearing a reality, a social worker in her own right. And Andrea Cetlin, an intern in my office, who worked with Susan long and arduous hours to put this together.

Finally, I would say that my own interest in this issue was stimulated about 1½ years ago in my mobil office by a woman who is here today in the audience and who came to see me with her young son and told me what it was like for her as a housewife raising small children to find that her husband disappeared over the course of a few months—at that time in his late 40's—and what it was like to try to go out and try to get a job, to provide the resources necessary to put her husband in a home where she would go to visit him during the week, and they wouldn't have cleaned the bedclothes or even changed his underwear, and to bring him home on weekends where he wouldn't recognize his children, and if left in the kitchen would take apart the stove, and the kind of impact that, needless to say, if one thought for just a few moments, that it could have on a marriage or on a family that had a burden that it could represent.

It is the kind of disease that is not only a killer, but it is very destructive to some American families and it is my hope that hearings like this one, hearing expert testimony, will start to provide some of the initial answers we need to build the statistical base which will not only provide resources, support services to families, but also perhaps begin to provide the information that will detect this disease at an early enough stage so that with medication and treatment down the line it can be stabilized rather than become so quickly destructive.

I, again, want to thank Chairman Downey for conducting this hearing. I also look forward to hearing the expert testimony with all of you.

[The prepared statement of Mr. Mrazek follows:]

PREPARED STATEMENT OF REPRESENTATIVE ROBERT J. MRAZEK

Thank you, Mr. Chairman. I'd first like to thank my colleagues from the House Select Committee on Aging for taking the time today to attend this hearing and to thereby grant official status to the proceedings. I am confident that the testimony of those individuals who are personally and professionally involved in the care, treatment and cure of Alzheimer's patients will be of tremendous aid to the committee as it considers a federal role in the alleviation of this national tragedy. The experiences of our witnesses today should help us to better understand this cryptic disease, and the problems faced by its victims and their loved ones.

Mr. Chairman, Alzheimer's's disease is a steady, irreversible, untreatable and ultimately fatal disease that afflicts an estimated 2 million Americans and kills over 120,000 people each year. It is the fourth leading cause of death after heart disease, cancer and stroke. This devastating dementia is most common in people over 60 years of age, but it has been diagnosed in people in their 40s and 50s.

Early detection of Alzheimer's disease is difficult, since at first it exhibits only minor symptoms of memory loss and mental deterioration which can easily be concealed, or attributed to other causes. As the disease progresses, there is difficulty in concentrating, poor judgment, disorientation to time, place and person, and, at some point, the inability to communicate. Some Alzheimer's patients may become agitated and abusive, while others become withdrawn. Eventually, those afflicted become totally dependent on family care providers, community services, and health-care institutions.

Alzheimer's disease poses enormous problems to the families of victims and raises complex social and economic issues for the public. Although science has made some important breakthroughs, there remains, at present, no treatment or cure for the disease, and no standard method of diagnosing it. Because of limitations in the structures of state and federal programs, families of victims receive inadequate financial assistance. Current insurance policies do not allow reimbursement to be made for custodial care provided to Alzheimer's patients. Families of victims must deplete all of their resources and savings before being elligible for Medicaid. There are few respite care facilities available to families with Alzheimer's victims. At present, there are only four day-care centers on Long Island that serve the Alzheimer's population.

It is my feeling that the disastrous plight of those afflicted by Alzheimer's disease, as well as the heartaches endured by their families, are issues that must be addressed. The testimony we hear today will reflect the myriad of problems associated with the treatment and care of Alzheimer's victims, and the goals and progress of research conducted in the field. I am hopeful that this information will increase our understanding of Alzheimer's disease, and enhance our perspective on what needs to be done in the future.

Congressional concern about Alzheimer's disease has focused on funding for research on the causes and treatment of the disease, and on the cost of care. Since there is no effective treatment or cure, many Alzheimer's patients are cared for in nursing homes in the latter stages of the disease. The estimated cost of this care now reaches $30 billion annually. Approximately $12 billion of this money comes from federal sources. Through the "Health Research Extension Act of 1985 - P.L. 99-158," Congress has authorized the National Institute on Aging (NIA) to make one or more grants to develop a registry for the collection of epidemiological data concerning the incidence of Alzheimer's disease and to train personnel in collecting such data. The Institute's appropriation bill for FY 1986 designates $2.5 million for this purpose, and they are presently reviewing research applications.

I have cosponsored two pieces of legislation directed at the problems of Alzheimer's disease. One, the Comprehensive Alzheimer's Assistance, Research, and Education Act (H.R. 2280, Roybal), would authorize $34 million annually for funding of 10 additional Alzheimer's research centers, special Alzheimer's family-support projects, 10 state Alzheimer's programs (50/50 matching grants to set up programs, to help train providers, to educate the public, to look at state Medicaid and other policies relating to Alzheimer's, and to help set up respite care), a National Alzheimer's Education Program (to increase visibility of the issue), and Medicare and Medicaid research and demonstrations. This bill is pending in the committees of Energy and Commerce, and Ways and Means.

The second piece of legislation, H.R. (Bilirakis), would direct the Secretary of Health and Human Services to conduct at least 10 demonstration projects to determine the feasibility of providing Medicare benefits for individuals diagnosed with Alzheimer's disease or related memory disorders. $10 to 15 million would be allotted for a one-year experimental program. This bill is pending in the Energy and Commerce, and Ways and Means committees and is likely to pass.

Mr. Chairman, the attendance and participation of all those here today will enhance our understanding of the realm of these problems, and aid us in our battle against Alzheimer's disease, giving hope to the two-million-plus Americans who suffer from the disease and the countless more who are somehow affected by it. I again wish to thank the chairman and the distinguished member of the committee from Queens for their participation today, as well as those witnesses whose testimony we shall now hear.

Mr. DOWNEY. Thank you, Bob.

We are going to hear from our first panel, which we have called, for our own purposes, the "social panel." We will start with Ms. Ellen Tolle, the president of Alzheimer's Disease and Related Disabilities Association, Long Island Chapter.

Ms. Tolle, you will go first, to be followed by Ms. Walsh, Ms. White, Ms. Kennedy, Mr. Arfin, Dr. Steffins, and Mr. Schneider.

I have here your biographies, which I will not read, but they will all be submitted for the record at this time.

Ms. Tolle, if you will begin.

BIOGRAPHICAL SKETCH OF EACH WITNESS TESTIFYING BEFORE THE SELECT COMMITTEE ON AGING, FIELD HEARING ON PROBLEMS ASSOCIATED WITH ALZHEIMER'S DISEASE JUNE 21, 1986 :

Ellen Tolle, R.N., MPS

Ellen Tolle received a BS degree in nursing from Long Island University in 1973, the year in which she also received a Nursing Departmental Award. Between 1971 and 1980, Ms. Tolle was the Head Nurse of Medicine at Peninsula Hospital Center. She performed allergy testing between 1981 and 1984. In 1984, she became the director of "The Club," an Alzheimer's day program. She is the President and Co-founder of the Long Island Chapter of Alzheimer's Disease and Related Disabilities Association.

Janet Walsh

Janet Walsh attended John Day College of Criminal Justice. She worked as an Option Trader for Oppenheimmer and Company, Inc. from 1975 to 1979. Between 1979 and 1982, Ms. Walsh was a member of the American Stock Exchange. Janet is a member of the North Shore Business Forum. She is a political fundraiser, and she is active in raising money for the Stony Brook Foundation for the Center for the Study of Aging. Ms. Walsh is married and has three children.

Edna White, R.N.

Edna White has been a registered nurse since 1966, when she received her nursing degree from Suffolk County Community College. She received a BA in Health Administration from St. Joseph's. Edna practiced nursing in Central Islip Hospital from 1960 to 1964. She worked at Huntington Hospital between 1963 and 1985. In 1985, Ms. White began private nursing in homes and in hospitals. She has been a support group leader for Alzheimer's victims and their families since 1983. Edna has been on the Alzheimer's Disease and Related Disabilities Association since 1984.

Shirley Kennedy, A.C.S.W.

Shirley Kennedy received her Master's degree in Social Work from Adelphi University in 1975. She attended Brookdale Post Master's Program in Gerontology. Ms. Kennedy developed a support and counseling program for older adults with Alzheimer's disease. She is the Supervisor/Coordinator of the Sr. Health and Counseling Service of the Angelo J. Melillo Center for Mental Health. Ms. Kennedy is a member of the Council on Aging of the National Association of Social Workers.

Paul Arfin, MSW

Paul Arfin received his Master's degree in Social Work from Adelphi University. He has been working in non-profit agencies since 1967, providing counseling, community education, and community organization services. Mr. Arfin has been the Executive Directive of Community Programs Center, a day program for the frail elderly, since it started in 1980. He is on the Board of Directors of Suffolk Community Council.

Dr. Timothy Steffens

Dr. Timothy Steffens received his Bachelor's and Master's degrees in Administration from Hofstra University. He received a Doctoretie in Theology from Clarkston University. He has been a nursing home administrator for thirty years.

Ira Schneider, Esquire

Ira Schneider received his Bachelor's degree from New York University in 1970. In 1973, he received his Law Degree from Brooklyn Law School. Mr. Schneider is the former Managing Attorney of Bronx Legal Services Office of the Elderly. He has been a partner of Robert and Schneider, Attorneys at Law, since 1980. Mr. Schneider specializes in law for the aged and disabled populations.

Paul Helms, M.D.

Dr. Helms attended the University of Texas Medical Branch, Galvaston from 1974 to 1978 and did his internship in family medicine at the University of Iowa from 1978 to 1979. His residency was at the University of Iowa with the Department of Psychiatry from 1979 to 1982. In 1982 Dr. Helms joined the staff at the State University of New York at Stony Brook as Assistant Professor of Psychiatry. He is also Staff Psychiatrist at University Hospital, Stony Brook. In addition, Dr. Helms is a consultant to St. James Alzheimer's Day Care Program and the Director of the Geriatric Psychiatry Program at University Hospital, Stony Brook.

Ronald M. Lazar, Ph.D.

Dr. Lazar received a Bachelor of Arts degree from New York University and a Ph.D in Psychology from North Eastern University. Post Doctoral Education included two years each at Georgetown University and a Eunice Kennedy - Shriver Center for Mental Retardation. He has been a staff member in the Department of Psychiatry at New York Hospital and in the Department of Neurology at North Shore University Hospital. In 1982 Dr. Lazar was awarded an Andrew W. Mellon Fellowship in the Department Neurology at Memorial Sloan Kettering Cancer Center where he later became an attending psychologist. At present Dr. Lazar is Assistant Professor of Neurology at the Down State Medical Center School of Medicine and Director of the Neuropsychology clinic at State University Hospital in Brooklyn. He is also Chief Neuropsychologist at Kings County Hospital and a member of the Professional Staff in the Department of Medicine at the Community Hospital at Glen Cove. Dr. Lazar has a private practice at Old Brookville on Long Island.

Maynard H. Makman, M.D., Ph.D.

Maynard Makman received a Bachelor of Science Degree in Chemistry from Cornell University in 1955. In 1962, he received an MD and Ph.D. from Case-Western Reserve University, in Cleveland, Ohio. Between 1962 and 1964, Dr. Makman conducted research as a Fellow at the National Institute of Health. Since 1964, he has been conducting research at Albert Einstein College of Medicine. Dr. Makman's research has focused on neurotransmitters in the Central Nervous System and in the Aging of the Heart. He has been a Professor of Biochemistry and Molecular Pharmacology since 1979.

Fritz A. Henn, M.D., Ph.D.

Fritz Henn is Professor and Chairman of Psychiatry at State University of New York at Stony Brook. He has a degree in biochemistry and a research interest in neurochemistry. His clinical work consists of studies on new drugs, including compounds which may enhance memory. This has led to the formation of a clinical service at Stony Brook, which specializes in the evaluation of dementia. The research work Dr. Henn is involved with includes an understanding of the differences in cellular function of classes of brain cells. Other work involves the localization of neurotransmitter receptors and an analysis of the pathways which are involved in memory and learning.

Richard C. Mohs, Ph.D.

Richard Mohs received a Ph.D. in psychology from Stanford University. He did a Post Doctoral Fellowship at Stanford Medical School. Dr. Mohs has been conducting research with Dr. Kenneth Davis since 1974. He has been associated with the Mt. Sinai School of Medicine and the Bronx Veterans Administration Hospital since 1979. Dr. Mohs was awarded one of the first five Alzheimer's research centers funded by the National Institute on Aging.

PANEL 1, CONSISTING OF ELLEN TOLLE, PRESIDENT, ALZHEIMER'S DISEASE AND RELATED DISABILITIES ASSOCIATION, LONG ISLAND CHAPTER, WOODMERE, NY; JANET WALSH, DAUGHTER OF AN ALZHEIMER'S VICTIM, SANDS POINT, NY; EDNA WHITE, REGISTERED NURSE, PRIVATE NURSE FOR ALZHEIMER'S PATIENTS, CENTERREACH, NY; SHIRLEY KENNEDY, A.C.S.W., COORDINATOR/SUPERVISOR, SENIOR HEALTH AND COUNSELING CENTER OF THE ANGELO J. MELILLO CENTER, STONEY BROOK, NY; PAUL ARFIN, M.S.W., EXECUTIVE DIRECTOR, COMMUNITY PROGRAMS CENTER OF LONG ISLAND, NY; DR. TIMOTHY STEFFENS, ADMINISTRATOR, BIRCHWOOD NURSING HOME, HUNTINGTON, NY; AND IRA SCHNEIDER, ATTORNEY AT LAW, HEMPSTEAD, N.Y.

STATEMENT OF ELLEN TOLLE

Ms. TOLLE. I would like to thank you for the opportunity to present this testimony on behalf of the Nassau-Suffolk County Chapter of the Alzheimer's Disease and Related Disorders Association, hereafter referred to as ADRDA.

The Nassau-Suffolk Chapter is one of 126 chapters and affiliates in the country belonging to the national organization. In late 1982, there were three support groups throughout both counties, and it was through their efforts and perseverance that our chapter was formed and incorporated in 1983. Since that time we have grown from the initial 3 support groups to the present 16 groups. Our mailing list has grown to 1,600. Our office, which is starting its second year, responds to all inquiries and requests for information and assistance that comes to our chapter from local referral and from national ADRDA. In all of 1985 we responded to about 1,000 requests by phone and mail. In the first 5 months of 1986 we have already had 755 requests. We hope that in the near future our office, which is located in Hicksville and is open only 3 days a week, will be able to move to larger quarters to accommodate our growth and better assist the families that we serve.

On a national and local level ADRDA is committed to pursuing four goals: Family support, education and public awareness, research, and public policy.

Family support. The 16 support groups of our chapter meet once or twice a month attended by approximately 10 to 20 people per meeting. Some of our groups are led by professionals and others by family members. People who come to these meetings share experiences, discuss problems and frustrations, teach each other management techniques and support each other through times that words cannot accurately describe. There are times though when a support group is not enough to help the family cope and professional help is advised and encouraged. The formation and growth of support groups is an extremely important function of our chapter.

Education and public awareness. Through our office, information packets are sent to all people who have contacted the chapter for the first time.

Our chapter is called on to participate in seminars, workshops, and health fairs. Our volunteers get requests to speak to community groups and participate at inservice sessions in hospitals, nursing homes, and home health agencies.

Throughout the year there are open-chapter meetings held at Brunswick Hospital Center. Speakers with expertise concerning Alzheimer's disease discuss topics concerning medicine, finances, law, nursing home placement, et cetera.

A chapter newsletter is sent to everyone on our mailing list. It contains professional articles, resources, updates, support groups, legislation and other pertinent information. The response from families indicate that it is well read.

Public awareness is given a real boost in November with "National Alzheimer's Disease Month." Television, radio and the news media help to relay information to millions of people.

Research. In 1986 the ADRDA national research budget of $1.8 million will support 33 new research grants and awards, along with three brain banks.

Our chapter supports research on a local and national level through contributions and encouragement. We try to provide the information requested of us by researchers to help them in their quest to find a treatment and cure for this disease.

We make every effort to keep chapter members abreast of research on a local and national level, including information concerning autopsy procedures.

Legislative advocacy. Although Alzheimer's disease has become well publicized there is still an urgent need for change in many policies that affect our families.

To affect these changes on a national level means Federal involvement. National ADRDA and local chapters work hard to help our elected officials understand the needs and concerns for the future and ask that they lend their expertise to our cause.

Besides our four main goals mentioned above, we are involved in fund raising efforts to help support existing Alzheimer's day care and respite centers and to encourage the growth of these centers throughout Nassau and Suffolk Counties.

Last year the chapter gave three day care grants.

Needs and problems. Alzheimer's disease is a disease that affects not only the person with the diagnosis, but the entire family. It is a disease that destroys many family units. In some cases it causes siblings to fight, adult children to divorce and healthy spouses to become ill or die. It is a disease that isolates the family and causes the caregiver to become a virtual prisoner in his own home. It is a disease that progresses, causing most of the affected to become totally dependent on others. This means round-the-clock supervision and care. Most of our families accept this burden of care beyond the limit of endurance. We are only human and our finely tuned machines, after enough wear and tear, breakdown mentally and physically. To prevent this breakdown a continuum of supportive services are needed.

Financially our families are drowning. Many have depleted their savings; some spouses have been forced to divorce; and others have manipulated their finances, all to obtain the necessary care for their loved ones. And while this care is prohibitive in cost, the quality in no way equals the expense.

There seems to be a built-in competitiveness with service agencies that causes fragmentation of care, rather than building blocks for comprehensive services.

Day care and short-term residential or institutional respite centers that care for people with Alzheimer's disease are scarce. Most community programs that deal with the frail elderly will integrate a small percentage of people with Alzheimer's disease into their programs, but impose restrictions such as no wandering, so that it becomes impossible for many of our families to utilize their service.

Day care for our population is not only a necessity for the caregiver, but an integral part of the diagnosed person's life. These centers are a place of acceptance and security. A place to socialize and make friends. A place that helps to increase self-esteem and to retain ones dignity.

People should not have to travel for miles to avail themselves of this type of service. Community programs must work together to find a way to implement small local day programs for people with dementia.

Our families need home care at affordable prices. Many families use home health aides on an intermittent basis, some need round-the-clock help and others need daily help so the caregiver can continue to work. At the present time the average cost to the family for a home health aide is $7 to $8 an hour. If live-in help is necessary, the cost is about $80 a day.

Private assistance through supplemental and other health insurance policies are almost nonexistent because it is considered custodial care.

The majority of our families are not wealthy. They have some money, but not enough to afford the amount of home care needed. Is the answer Medicaid? At the present time what are the other financial alternatives?

Money must be appropriated to set up training programs for health care workers so that families are assured of qualified, knowledgeable and caring health care providers.

The following are some statements about the nursing home situation:

The average nursing home cost on Long-Island is $4,000 a month.

Families are told that there is at least a 6-month waiting list when placing someone from home.

Families are told that they must pay privately for 3 to 6 months before the nursing home will accept Medicaid.

If placement is from a hospital, the person must be placed within a 50-mile radius.

Nursing homes look at the person with Alzheimer's disease as less than desirable candidates.

How are families to contend with all this? The decision to place a loved one is not easy to come by and most times there are feelings of guilt and sometimes a feeling of failure on the part of the caregiver.

Long-term care facilities are not equipped to handle Alzheimer's patients. Problems such as staff shortages, poor facility design—especially lack of large, safe areas, and lack of therapeutic programs—makes caring for the Alzheimer's patient difficult. Due to these circumstances, the nursing homes resort to physical and chemical restraints and limited admission for people with Alzheimer's disease.

Many staff members are not highly motivated, are apathetic and untrained to care for people with dementia or to be supportive to their families.

Our long-term delivery system must be reevaluated to assist not only the plight of the Alzheimer's families, but also the growing demand placed on us as a whole by the aging of our society.

Last, although there has been some progress in research, many questions are still unanswered. The magnitude of the research effort necessary to combat this illness can only be accomplished if the Federal Government becomes serious and mounts a priority effort to help answer the baffling questions that remain.

Mr. DOWNEY. Thank you, very much.

Ms. Walsh?

STATEMENT OF JANET WALSH

Ms. WALSH. I am going to try and compress 9 years into 5 minutes, to try and let you understand what it is like to have someone in your family with Alzheimer's disease. It is still very hard for me to talk about this, but I need to do it because I want others not to have to go through what we did.

My father led a very full and energetic life and our home was a very happy one. He was chief engineer of a refrigeration firm, commander in chief of our local American Legion, and a sergeant in the police auxiliary. My father was an avid hunter and fisherman, and always provided a secure environment for his family.

The disease started without any medical incident; that is, a fall, stroke, et cetera. At first only my mother sensed something was wrong. My father would call and say he got lost on a hunting trip. He hunted those particular woods all his life and was an excellent tracker. Then the call would come from somewhere local, again, he couldn't remember how to get home. I was 15 at the time and quite concerned when my father would drive through a stop sign as if it were not there. My parents began to argue frequently, which I interpreted as they didn't love each other and were headed for divorce. Needless to say, the tension was mounting in our home. I kept hoping that one morning I would wake to find everything back to normal. Normal cannot be used to describe what followed.

After repeated incidents of paranoia and the inability to cope with everyday things, we took my father to his physician. The doctor informed my mother that my father was suffering from hardening of the arteries and she should watch him, but not so much as to annoy him. He was given medication to help soothe his anxiety.

Shortly thereafter my father was forced into early retirement by the company he had worked 30 years for. It was 1971 and he was 60 years old. The union my father belonged to interviewed him in my presence and found him competent to hold down a job and, therefore, found him one. You must understand my father still had days when he was as normal as anyone else, they were just becoming fewer and fewer. The new job lasted a week, and it was determined that my father didn't want to work. Neither our doctor nor the union doctor that examined him would put down on paper a diagnosis that would enable him to retire disabled and, therefore,

we were forced to accept the smallest pension which amounted to $400 a month. My father previously earned in excess of $30,000 a year, not including the tremendous overtime he would put in. Social Security benefits were at least a year away with all the paperwork and processing. Fortunately for us my mother had taken a part-time job so that I could attend parochial high school. So, all of a sudden the future was quite dim for us. For the next year my father was constantly supervised to the best of my mother's, my 2 sisters' and my ability. Needless to say, things got much worse. It was becoming apparent that my father could no longer handle even the simplest of tasks.

My mother never drove a car so we had relied on my father for transportation. Now, this man was incapable of driving a car and we had to pretend that the car was stolen to get it away from him. Similar deception, unfortunately, had to be used to remove the gun my father carried as a police auxiliary sergeant, and also his entire collection of hunting rifles. He was accusing the neighbors of stealing his wallet and personal belongings; we didn't want him to have access to anything that might bring injury to himself or anyone else.

All hopes of attending a college away from home were thrown out the window in my senior year of high school. I attended the city university in the fall of 1973, and held down a job in the college bookstore to support myself. My mother helped as best she could. It seemed that somehow, before my father left his job, he took out two bank loans with two different banks and we had no idea where the money went and my father had no recollection of getting the money, so my mother's financial burden was even greater.

Our home was turned into a prison. All doors and windows had to be kept locked. He had to be watched 24 hours a day. It seemed he never slept. My father had started to hallucinate the craziest of things, and could have easily fallen down the stairs.

At one point the strain became so much that I came down with walking pneumonia and had to be hospitalized for 2 weeks. At that time the house psychologist had suggested that I seek therapy because he felt the pain in my chest was a result of stress. I was only 18 at the time and had heard of therapy only on TV for the very rich or the very crazy. If only he had told me about the clinics in our area that didn't charge someone in my position. I told him I didn't have the time or the money for that and would handle it myself. I consider that a point in my life when someone had the chance to help me, a professional who could obviously see the emotional pain I was in, and just passed on the opportunity.

Soon after my return from the hospital my father became violent. My father had never laid a hand on any of his children and would certainly never strike my mother, but strike my mother is exactly what he did. At that time my sister knew a neurologist at our local hospital and she asked him to see my father. The neurologist put my father through some testing and concluded that my father was suffering from Alzheimer's disease. It was 1973 and we had never heard of this disease, and it would be many years before we would see anything in writing describing the disease in nonmedical terms.

My father remained in the private hospital for 6 weeks, most times heavily sedated or in a straitjacket, while we tried to find permanent placement for him. Fortunately, my father was a veteran and was accepted to the Northport VA Hospital in Northport, Long Island. Once in the VA system, at least we knew he would be cared for and, hopefully, return home when he was all better. Obviously, we were very disillusioned. The day he was admitted to the hospital they told us we would be unable to visit with him for a period of 2 weeks while they removed him from the heavy sedating drug to something milder, and also acclimated him to his surroundings. Those 2 weeks went on forever in my mind. I was happy to get a good night's sleep and not have to worry about what outburst my father would have next, but I also missed him very much. When we finally did see my father, we sat at a big table in what looked like a conference room, and we all cried with him. He didn't recognize me then and never did again.

In the beginning my father was allowed to come home on weekends and holidays. The house turned into a nursing home when he came home, and we all took turns caring for him. Most of the burden, of course, fell on my mother. One day, while I was bathing my father, I stepped out of the room to get something. When I came back I found my father fully submerged in the tub. I yanked him up and screamed, "What are you trying to do?" He looked at me square in the face and said, "Kill myself." If I had known then about all the years of agony for him to follow, I would have closed my eyes and let him do it.

After a while it became too hard for us to handle him at home, especially with his escaping out of the house. There was a day when he escaped from the VA hospital and found a car that was running and got in and drove off. The car was parked outside a grocery store and the owner just ran in to pick something up. She left a young child in the back seat of that car. Fortunately, the police pulled my father over and spotted his hospital band on his arm.

The VA was really not equipped for someone with the early stages of this disease, so my father was placed with mostly young Vietnam veterans who were suffering from their own hell. My father ended up in several brawls with these young patients and suffered a classic black eye on a few occasions. Eventually the disease started to get the best of my father physically, and a wheelchair was required to get around.

The deterioration finally started to increase rapidly and by his third year at the VA hospital he was confined to a chair. He remained at that hospital, shifting in and out of bed or chair, for 4 more years. Each year the disease took more and more of the man I had called father, until he died on February 20, 1981, a mere skeleton.

We need a cure for this deadly disease. I have many more heart rendering stories to tell, but I think everyone will get my point. Family members need help both emotionally, financially, and with respite care. With each Alzheimer's victim dozens of other lives are deteriorating also.

Thank you.

Mr. DOWNEY. Thank you.

Ms. White?

STATEMENT OF EDNA WHITE

Ms. WHITE. Medicare patients admitted to our hospitals today have their hospital stay and care regulated by Medicare Diagnosic Related Groups. These regulations designate the funds and the length of time allotted for each admission. In order for the hospital to save funds, the patient may be discharged before the allotted time period. The savings realized by early discharge of the "average" patient could be used to care for the patient who cannot be released with the specified time due to complications.

Because of the cutbacks in funding for our Medicare patients, hospitals can no longer afford adequate personnel to give the same, good, complete patient care as they did in the past.

The well-oriented patient admitted to our hospital today can understand instructions, ask for assistance, and communicate feelings of pain or other physical discomfort. However, these patients may also become disoriented due to the trauma surgery and anesthesia and be in a state of confusion, lasting for several days following discharge. The spouse or other family members may not be able to provide the care required by the patient, and assistance from home health care agencies is often required. Home health care is very costly. Assistance for this service by Medicare is very limited and to receive assistance from Medicaid a family must exhaust almost all of its assets.

Because of memory loss and confusion suffered by the Alzheimer's disease patients in their own home, confusion and fear are intensified when these patients are admitted into the hospital. The patients may become hostile or abusive because they cannot understand what is happening or expected of them. Todays strict time schedule and heavy work load does not allow for the understanding needed for the proper care of the confused Alzheimer's disease patient. Bathing is a fearful experience for the Alzheimer's patient, who may become uncooperative when forced to adapt to the hospital schedule. Medications are also feared. These may be refused or taken and held in the mouth to be spit out at a later time.

The Alzheimer's disease patients cannot make their needs known nor can they express discomfort. A shoulder brace for a dislocated shoulder may be removed by the patient as he cannot understand the reason for this uncomfortable device. Apprehension may also be caused by the use of restraints for the protection of the patient.

The patient who wanders presents a very serious problem both in the hospital and in the nursing home, which is regulated by resource utilization groups. These patients, unless carefully observed and supervised, may cause serious harm to themselves or others. The Alzheimer's disease patient could walk into a contaminated area, into a diagnostic testing department or find the way to exit from the facility.

The unsteady gait of these patients is another serious hazard that cannot be neglected. Falls, causing dislocations or broken bones are a needless additional burden for the confused Alzheimer's patient to bear.

Although the Alzheimer's disease patients may be able to feed themselves at one meal, they may lose this ability by the next mealtime. It is imperative that the health care worker understand this and not consider the patient merely to be cantankerous. Encouraging eating and the necessity of feeding these patients is not only vital to their health, but time consuming for the health care worker. This procedure may consume 1 hour or more of extreme patience.

The uncommunicative, nonambulatory Alzheimer's disease patient requires the same intensive, continuous care as does the patient who is comatose. Their needs must be anticipated by knowledgeable health care workers.

Many of our routine practices in the hospital must be carefully re-evaluated in caring for the Alzheimer's disease patient as some of these seemingly routine practices could be hazardous. It is not unusual to leave supplies required for treatments in a patient's room. Nor is it unusual to leave an oral glass thermometer for the patient's own use. However, the Alzheimer's disease patient may not realize what this object is and attempt to eat it. Any objects left in the room of the Alzheimer's disease patient should be thoroughly assessed for possible accidental harm.

The routine drawing of blood for diagnostic tests cannot be completed in the same timeframe allotted for the cognizant patient. The application of a band-aid and the instructions by the medical technologist to apply pressure to the site may be misunderstood by the Alzheimer's disease patients. If not carefully observed by the technologist, they may possibly remove the band-aid, causing bleeding from the site.

It is unfortunate that so often the charts of the Alzheimer's disease patients contain the words, "uncooperative, hostile, physically, and/or verbally abusive." If family members were not restricted to specified visiting hours they could help to assist the hospital personnel in the patient's care as the presence of a loved family member helps to allay their fears of strange surroundings. Hospital personnel should be made aware of the advantages of allowing family members as much time as they feel may be needed for the proper care of the patient.

Our medical facilities are understaffed and the DRG's and the RUG's do not make allowances for the time-consuming care needed for the Alzheimer's disease patient. We must carefully explore these policies and make appropriate financial changes to provide the necessary care, without the loss of dignity to the patient.

We must consider the policy that exists today in our veterans hospitals that refuse care to the Alzheimer's disease patient who does not have a physical problem. These hospitals should be obligated to care for those citizens who offered the possible loss of their lives to serve our country.

We need funding to help provide care at home for the Alzheimer's disease patient upon discharge from the hospital. These patients may be returned to a spouse who may also be suffering from a physical disability or to a family member who cannot provide the necessary 24 hours of care.

We need funds to provide more geriatric screening teams that can enter the home and assist in the regulation of medication, care,

and in placement of the family member when necessary, instead of the need to call the police for assistance and have the patient and the family suffer from the indignities associated with this form of assistance.

Above all, we should have funds allocated from the State in conjunction with our New York State ADRDA chapters to educate and train all of our health care workers in the hospitals, nursing homes, State and Federal facilities and the voluntary medical personnel in our rescue squads in the care of the Alzheimer's disease patient.

The Alzheimer's disease patients have not requested this fate. They have the right to be treated with dignity and respect until death.

A post script, I would like to add that I am also a family member of an Alzheimer's disease victim. My mother has been affected since 1965 and is still alive. In 1982 the intolerable nature of this disease took the life of my father, a very well, healthy man. He was stricken by a massive myocardial infarct; it almost claimed my own life as well.

Thank you.

Mr. DOWNEY. Thank you, Ms. White.

Before we hear from Ms. Kennedy, let me say, we are glad we have been joined by our colleague from the other part of Long Island, Queens, NY and a member of the Aging Committee, Congressman Manton.

Tom, do you have an opening statement we can submit for the record?

Mr. MANTON. If there is no objection, I will submit my statement for the record.

Mr. DOWNEY. No objection. It is so ordered. Your statement will become a part of the hearing order.

[The prepared statement of Representative Manton follows:]

PREPARED STATEMENT OF REPRESENTATIVE THOMAS J. MANTON

I WOULD LIKE TO THANK CONGRESSMAN MRAZEK FOR SPONSORING TODAY'S HEARING ON ALZHEIMER'S DISEASE. CONGRESSMAN MRAZEK'S LEADERSHIP AND HIS COMMITMENT TO THE ELDERLY ARE WELL KNOWN IN THE CONGRESS, AND THIS AFTERNOON I AM DELIGHTED TO BE JOINING HIM AND CONGRESSMAN DOWNEY, WHO IS ALSO AN EXCELLENT ADVOCATE FOR THE ELDERLY. THE RECORD DEVELOPED TODAY WILL GREATLY CONTRIBUTE TO OUR EFFORTS IN THE CONGRESS TO [redacted] FORMULATE A POLICY TO MOST EFFECTIVELY HELP OUR NATION'S ALZHEIMER'S VICTIMS.

ALZHEIMER'S DISEASE IS ONE OF THE MOST SERIOUS PROBLEMS FACING OUR STATE AND OUR NATION TODAY. OVER 2.5 MILLION AMERICANS SUFFER FROM ALZHEIMER'S DISEASE. THIS IS A DISEASE WHICH EXACTS A TRAGIC COST FROM THE SPOUSE, FAMILY AND FRIENDS OF AN ALZHEIMER'S VICTIM, AS THEY WATCH A LOVED ONE DETERIORATE UNDER THE SPELL OF THIS TRAGIC DISEASE THAT HAS NO CURE.

Mr. DOWNEY. Ms. Kennedy, we will hear from you.

Ms. KENNEDY. I ask you to give me a 4-minute warning.

Mr. DOWNEY. You can see the emotional nature of the testimony. I don't think it would be appropriate to cut you off at any time. Just proceed with your testimony.

STATEMENT OF SHIRLEY KENNEDY

Ms. KENNEDY. Congressman Mrazek, Chairman and Congressman Downey, thank you for the opportunity to present this testimony.

I am Shirley Kennedy, social worker coordinator supervisor of a program called Senior Health and Counseling, which has been a unit of a mental health center, the Angelo J. Melillo Center for Mental Health, for over 12 years, serving the city of Glen Cove and the villages within the town of Oyster Bay around the city of Glen Cove.

My total years of working in Nassau County as a social worker are 12 years. Since 1978, this program has assisted Alzheimer's disease victims and their families. An interdisciplinary team of nursing and social work staff address the problems facing older adults—and I do say "older" because we are limited to those 60 and over here; one of the restraints of our program is that we have to adhere to the funding requirements—through the provision of mental health, physical health and social services. The strength of this program is in the service integration and team coordination and two-staffed community offices in two local village halls, with health assessments for health maintenance and wellness promotion in nine other community sites, such as churches, housing, village halls, and libraries. Also, there have been the backup services of the Mental Health Center for Psychiatric, Psychological, and Psychotherapeutic Services.

Our early services for Alzheimer's disease began about 8 years ago for victims and relatives, and included home visits, health education and counseling for those coping with a lack of information about Alzheimer's disease within the medical profession and the general public. Panic and despair faced families as they groped with the vicissitudes of total ignorance, lack of services, and lack of health care coverage, and nowhere to go for answers in 1981. Support groups for family members of Alzheimer's victims were established. These have continued under the leadership of nursing, social work staff, and student interns and volunteers.

Senior health and counseling services served as a hotline for a short time for Alzheimer's disease inquiries on the North Shore, until the formulation of the staffed offices of ADRDA for Nassau-Suffolk. Inquiries came from far afield: New Jersey. Westchester, New York City, and Nassau and Suffolk. Even though the service area of our agency is limited to the communities surrounding the Mental Health Center, we responded to the needs as the lack of services and resources and information was so great that it would have been heartless to turn people away because of proscribed service limitations.

In 1984, the sponsor of the Angelo J. Melillo Center for Mental Health requested, and received, a grant from the Long Island Com-

munity Fund for a planning study leading, hopefully, to the establishment of a daycare center for Alzheimer's disease victims.

Our survey of 135 physicians and health care providers received over a 44-percent response. These health care providers were prepared to refer 900 Alzheimer's victims sufferers for adult daycare service. In the spring of 1985, the department of senior citizen affairs put out a request for proposals for adult daycare for frail elderly. Our proposal was submitted and it was denied.

Individual and group services continued. For the care giver, respite from the burden of home care responsibilities, the catharsis of sharing with others, learning from each other and learning from resource experts about problems such as financial arrangements, current research and developments in the field of medicine, behavioral effects and health care finances are all a part of the group program. Information, referral, home visiting, problem solving counseling, personal counseling and liaison with other providers of services, residential health care placement, advocacy through Medicaid and Medicare adjudicatory appeal sometimes are some of the concrete services that we provide.

In this northwest peninsula pocket, and I really mean it as a peninsula—we are an isolated penninsula in Nassau County—there is one adult daycare center that will accept Alzheimer's disease victims, only in the earliest stages, and because of staff limitations, someone who needs assistance with toileting cannot participate because of the need of the nursing director to have lunch. What is most critical is what is not available. I would like to say that this daycare center is sponsored by the Glen Cove Senior Center.

What is not available? Home health care personnel are scarce. Home health care coverage is scarce. And if someone is not 60, they are not eligible for Medicare anyway.

It is not an acute, but a chronic care disease; it is left out of many funding resources. The scarcity of services for both individual and groups is devastating for both the victims and their families when faced with this degenerative disease. Even a residential health care facility does not have enough beds to meet the needs and the model facility of an enclosed campus; intermediate care facility level for the A.D. victim and other cognitively impaired victims are nonexistent in our two counties.

These meager services of senior health and counseling services are now no longer to be available to the Alzheimer's disease population or anyone. The years of staff experience, the individual and group services are scheduled to end. The Nassau County Department of Senior Citizens Affairs has canceled its contract with the Angelo J. Melillo Center for Mental Health or Senior Health and Counseling Services Center for Case Management. There is a countywide consolidation plan to consolidate case management of services. What it is doing to our unit of interdisciplinary care is legally cannibalizing it. This means the Alzheimer's disease programs, our health, wellness promotion, social services, and home services are to be eliminated, phased out entirely as of September 30.

Unfortunately, in Nassau County, there exists a lack of concern at the top levels of planning for social and health care promotion. Alzheimer's disease is defined by the commissioner of mental health as not a mental health disease and, therefore, not eligible

for funding, not even for support groups within the mental health funding source. This same department of mental health developed and funded, through its mental health centers, group programs for relatives of cancer patients some years ago. How I can understand that is beyond me.

Alzheimer's disease is the orphan of diseases. Hospitals and some nursing homes discriminate against Alzheimer's disease patients for admission. There are too few geriatrics facilities. Geriatric patient training is limited and very limited in the area of senile dementias. Medicare discriminates against the Alzheimer's disease patient. If we say that the client goes where the money goes, this is a double jeopardy for the Alzheimer's disease patient and family. The money must be unlocked and unblocked and channeled to meet the needs for this destitute population. There are no services for those under 60 years of age within the Department of Senior Citizen Affairs. We find there are Alzheimer's disease patients, of course, in their fifty's some in their forty's so that we are stuck by the petrified, calcified channels of funding resources in this county.

Thank you.

Mr. DOWNEY. Mr. Arfin.

STATEMENT OF PAUL ARFIN

Mr. ARFIN. My name is Paul Arfin. I am executive director of the Community Programs Center of Long Island, a nonprofit agency, headquartered in Dix Hills, NY. The organization operates two child care centers, one in Centereach and the other in Dix Hills. The center in Dix Hills also houses a day service for the frail and impaired elderly. The preschool children of working families and Alzheimer's patients interact on a daily basis. This program began in October 1984. It is because of this experience with Alzheimer's patients and their families that I am addressing the committee today.

The elderly day program primarily services Alzheimer's patients and their families. Since its inception 60 percent of the 65 enrollees have been diagnosed as having the illness. Some families bring their elder to the center 5 days a week. In other cases, a spouse brings a mate to the center. Some enrollees attend on a part-time basis, 1 or 2 days per week.

The center provides social and recreational services, not medical services. Nevertheless, analyses of the user-population demonstrates that there are no differences between our participants and the majority of patients in nursing homes.

The program is primarily financed through fees for services. State and county grants currently absorb approximately 40 percent of expenses. Because we provide no acute care or medical services, neither Medicaid or Medicare reimbursements can be used to pay for the services. Private donations and corporate giving cover 10 percent of the budget. Daily user fees range from $15 to $22.50, depending on whether transportation is provided.

Currently, our center provides services to Alzheimer's patients from as far away as Queens on the west, and Port Jefferson Station on the east, a distance of 60 miles. We also have participants from

Brightwaters on the South Shore and Kings Park on the North Shore.

The sad truth is that families have few viable care alternatives. Few centers accommodate Alzheimer's patients. Patients sometimes stray and can become agitated. In the 19 months of our program's operations, we have had to discontinue services to four people due to the intensity of their needs and our inability to meet those needs in an open setting. This is always a difficult and upsetting decision, since we know that we were probably the family's last alternative.

Originally, we planned to provide a caregiver for every seven elders. However, due to the high percentage of participants with Alzheimer's, we have had to make provisions for additional staff and volunteers. On most days we have a 5-to-1 ratio. Staff mainly consists of aides that help with programming, meals, exercise, reassurance, and companionship. Social work and recreation professionals function in supervisoral roles.

If there is one clear message that comes from our experiences, it is that families are extremely loyal and caring. They usually bend over backward to take care of their own. Families cope with constant stress for months and years at a time, not knowing how long they will be needed to assume the demanding 24-hour-a-day tasks involved. There often comes a point when the family can no longer cope. Outside help is brought in, or a residential setting is reluctantly chosen.

It has been estimated that dementia affects 15 percent of those over the age of 65. With the skyrocketing projections forecasted for the over-65 age group on Long Island in the next 20 years, we are going to be facing a jam or conflict within our families and our workforce.

The over-65 population in 1985 was 303,000, and is projected to be 422,000 by the year 2000. That means that there are 45,450 Alzheimer's victims on Long Island today, and there will be 63,300 by the turn of the century, only 14 years from now.

We are concerned about the stresses and conflicts that these realities place on families, including those in which the caregivers must remain in the workforce in order to make ends meet. As we all know, the two-breadwinner household has become the norm. I believe that caregivers who, for the most part, are women in their forty's, fifty's, and sixty's will increasingly be forced to choose between their commitments to earn a livelihood and to care for an aged relative. Hardworking families that want to care for their loved ones shouldn't be forced to make such choices. For some Alzheimer's patients, being left home alone so that a caregiver can be employed can lead to accidents and to fires.

Day centers can provide families with Alzheimer's disease a temporary alternative in the early stages of the illness. They provide: respite for the family; the opportunity for family members to be employed; mutual support; reinforcement to the family that it is the primary caregiver; and the greater meaning and purpose to the lives of the afflicted. Government should invest in financing new long-term alternatives to the institutionalization of Alzheimer's patients. One step might be to match the funds that families pay toward community-based alternatives such as day services. Govern-

ment helps families to pay for college through tuition assistance programs. It should also assist families to afford long-term care of the elderly that have been afflicted with Alzheimer's disease. Consideration could also be given to increasing the dependent care tax credit, which is currently equal to 20 percent of employment-related expenses paid by an individual who maintains a household which includes a dependent individual.

Revisions to Medicare and Medicaid that would permit reimbursements for day services should also be considered.

Day centers need to be professional-directed and supervised. They can be operated at considerably less cost than residential care alternatives. A day center can provide 5-days-a-week of care for $10,000 to $15,000 per year. Residential care often costs two-to-three times as much.

Most important to remember, however, is that people with Alzheimer's disease deserve to be treated with dignity and humane concern. While some of their behavior is childlike, unexplainable, and comical, they are deserving of respect and compassionate understanding.

Thank you for this opportunity to present our thoughts and concerns before you. If we can be of further assistance, please do not hesitate to call upon us.

Mr. DOWNEY. Thank you, Paul, for your testimony.

Dr. Steffens?

STATEMENT OF DR. TIMOTHY STEFFENS

Dr. STEFFENS. I consider this a privilege this afternoon to pass on to you, the honored Congressmen and the honored guests, some of my experience in approximately 30 years of working with the geriatric patient. I am second generation, so I am here by choice. My dad founded the first facility over 55 years ago. I am 56, so you can see I have been dealing with geriatrics for many years.

Up to about 1980 we very seldom heard the word "Alzheimer's disease." We heard the words "senile dementia," chronic brain syndrome. Only recently, in the last 5 or 6 years, have we found that even a few of the attending physicians have been willing to diagnose these type of people as Alzheimer's patients within the institutions. So, in reality—and I am only speaking for my own facilities, and I have about 600 institutional beds and I have a 125-person medical model day care facility, the only one in Nassau or Suffolk County.

Caring for this kind of patient is probably the most difficult thing to really accomplish. Without the proper training for the professionals that deal with these people on a daily basis, there will be no achievement whatsoever in stabilizing or minimizing the effects of Alzheimer's disease.

I am deviating from my speech, because that is what I normally do.

Mr. DOWNEY. Without objection, we will put your statement in the record.

Dr. STEFFENS. Thank you very much, Tom.

However, with proper training, with proper services, there is no question about it. The employees, the professionals of long-term

care settings, can be properly trained to take care of the Alzheimer's disease patients. I find right now in my institutions about 40 percent of the patients have some kind of dementia. Less than 20 percent have been diagnosed as Alzheimer's. There are probably many more, but as I earlier said, many of the attending physicians on Long Island, since they are not specialists in geriatric medicine, tend not to diagnose it as Alzheimer's disease.

Just to mention the day-care center, which I feel is probably the most important aspect of caring for these kinds of people in the early stages, we have a real medical model: We have transportation to and from our facilities; an 8-hour day, including transportation, fully paid for by Medicare. Anybody with Medicare that meets presently the lowest score under D.S. 1, can be admitted to our particular day-care center. We give complete care. We have attending physicians; we give complete medications, if necessary; we have dental care; we give bathing; we handle incontinency; and we handle the entire gamut that we find involved with Alzheimer's patients. We have M.S.W.'s on staff; we have a psychologist available whenever necessary; we have a chaplin on staff, on a part-time basis, to meet the spiritual needs of these people.

What we have tried to do in this environment is to make an environment that has the least amount of stress. My experience has indicated to me that an Alzheimer's patient will do the very best—irregardless if they are placed in an institution or at home or a day-care center—if they have the minimum amount of stress. We know that in a home situation, with the caring attitude of family, that can be readily achieved. It is much more difficult to achieve in an institutional setting, but if you have got the proper leadership, professional and spiritual leadership, we find that we do achieve and can achieve a minimum amount of stress with these kinds of people, considering the fact that they are placed within the four walls of an institution, even on a daily basis.

Our day care, incidentally, is open Monday through Friday, and all we have is Medicaid patients. We have no private paying patients whatsoever.

I have always grouped the Alzheimer's patient or senile dementia patients into three groups: One is the group that just needs general guidance in their aid to daily living. In reality it is done most of the time by the family, and they may not even need the day-care center, or a medical model day-care center. They can go to the center Paul has or some Mrs. Kennedy talked about, where they can receive their meals and social needs met on a daily basis.

The second group is the group that needs complete supervision and guidance done by professional people. Not the actual work, but the complete supervision and guidance done by these professional people.

Then, the final group, such as Ms. Walsh said when her dad was at the Northport VA Hospital. I have been there many times and I happen to live right nearby. These people need 24-hour skilled professional care. The costs can range in that particular area up to $50,000 a year because of the type of care they need. In the day-care center, presently, it is costing about $60 a day for us to maintain an individual, including transportation. We have a mileage radius of 15 miles for our medical model daycare.

As I said, we are licensed for 125. We are brand new. Our census, as of last week, was only 35. We are brand new and looking for you people that need this kind of assistance. We certainly are open for you.

We will, in our institutions, have a respite-type of program. And actually, we have people that bring their loved ones in on a 30-day basis. We make sure that it is a minimum of 30 days. I can recall right now two or three people, especially one that is a pilot in his early fifties that reached the point where the family really needs some respite, and every spring the wife comes and says, "Time, I just need it again for 30 more days. Whatever 30 days you have available, anytime during the spring, irregardless of the month, I need 30 days' rest." And we do that. We have at least a half dozen that we try to work with on a yearly basis in that type of situation.

There is no question, and I would agree with anyone else that previously spoke before me, that the family probably plays the most important role in this situation. Unless we, as the managers or administrators of institutions get the full cooperation of the family and the understanding of the family, what we try to do with them will really not be of tremendous success. So we certainly need the cooperation of the family. Not only in understanding what we are trying to do, but even volunteering and assisting. We have many of our dementia patients where the families come in routinely, and our volunteers, with mom or dad or with husband or wife. I am a firm believer that irregardless of how severe Alzheimer's disease might be, my inner feeling says that externally they may not recognize the family, but internally they certainly do recognize the family. I see the need for the family as very important.

Mr. DOWNEY. Dr. Steffens, can you sum up quickly?

Dr. STEFFENS. I am finished.

[The prepared statement of Dr. Steffens follows:]

PREPARED STATEMENT OF DR. TIMOTHY P. STEFFENS

I consider this a privilege, this afternoon, to pass on to you some of my findings relative to caring for an Alzheimer/dementia patient in a long term care setting.

Caring for this type of patient can very well be one of the most demanding tasks delegated to an employee of a long term care setting. This pertains to the professional nurses and the aides who may be involved in the actual laying on of hands.

I have been involved in long term care since the late 50's and caring for the Alzheimer/dementia type patient has certainly changed over that period of time.

The long term care environment must be so designed so that the patient's stress level be minimized, lending the patient toward minimal behavioral type problems.

Nursing homes have historically always had dementia patients and it has only been recently that we have so diagnosed them as Alzheimer. There is no question in my mind that the care given in the long term care setting has to become more personalized as we cope with the heavier care of the Alzheimer person. As administrator, I would like to group, in small areas, most of these patients, even if only less than 20% of the total patients are diagnosed as possibly having Alzheimer's.

My grouping would be as follows; one, where they need very little assistance in activities of daily living, secondly where they need total supervision in activities of daily living, and thirdly, where they need complete skilled and professional care in their activities of daily living. The facility should be so designed to house these three groups. The areas may be very small, depending upon the facility but clearly designed structurally so that the patient receives the minimal affect of institutionalization. Within this setting, their needs can be met. From my experience I believe that there is very little reversability to Alzheimer Disease, however, I do believe a structured facility could minimize or slow down this progression. The nursing homes of the 60's and 70's really did not blend to this needed care. In all three stages of progression it is important that we minimize the stress of the patient and the proper structure may very well be instrumental in minimizing this stress.

During the first stages of placement, the facility must be so designed that the individual feels that he or she is still in part of his own home and community. No way should a totally disoriented, noisy and disturbed patient be placed in this area as it would certainly increase the stress of this patient. A very disturbed, advanced case of Alzheimer/dementia should be placed in a third area where a high degree of skilled attention is available.

All staff should be thoroughly orientated and trained in caring for these residents. The further we move in this progression, the more skilled and more professional the staff should be. In fact, during the first stage of Alzheimer the patient could either remain in a private home situation or be placed in our typical custodial type setting such as an adult home or a residence for senior citizens. I have found that if we suddenly withdraw these people from their familiar surroundings, the dementia increases. The more confined they are in their setting, the care of the demented adult increases.

The staffing patterns are also directly affected by the three levels of care. For example, in an adult home you might need one licensed nurse to be supervisor and advise the custodial staff. This one licensed nurse may very well take care of a unit of 20 to 30 adults. While going to the third category you may even need, in some instances, professional care on a one-to-one basis.

I feel that the family must play an important role in all stages of this disease. The family must be continuously involved in the process of planning.

Many times we assume that the dementia adult loses the familiarity with its loved ones, however, my experience indicates that at various times during the day these people have had some desire for family relationship.

Dividing the Alzheimer/dementia adult in three stages or categories can make it much easier in the administration of medications. I feel that the dementia patients in their early stages do better with less medications than the ones who are given drugs. I have found that patients given medications at an early stage, deteriorate a lot faster than individuals who were started with less drugs or no drugs at all. I do realize that there may be other complicating medical problems that warrant the administration of drugs but, if at all possible, these drugs should be given only when absolutely necessary.

This is a challenge that many nursing homes must face. Unless they are willing to face this type of challenge, the patient will very rapidly progress to the third stage.

Since I am a nursing home administrator, I do feel that not only the staff, the family but the structure itself plays an important role. We cannot design nursing homes where dementia patients have nothing to do but walk around in circles or walk from one end of a corridor to the other. The structure must be so designed that even the frequent walking of the Alzheimer patients achieves some degree of satisfaction. The building must have areas that encourage activities that keep the individuals busy during their waking periods. I have found that music therapy is probably one of the most rewarding and stress-relieving activities. I have actually witnessed patients who were unable to sing but still able to recognize the song, either clapping their hands or tapping their feet. This little bit of activity sometimes satisfies the needs of the Alzheimer patient.

The units should be so designed that most rooms are private, with some rooms semi-private with two occupants only. All rooms in a cluster or possibly around a central day room. State design now prohibits this kind of facility but I am sure regulations will change as the state sees the needs of the dementia patient as a unit instead of mixing them with the entire population of the facility.

If each long term care facility would eventually dedicate a small area, possibly 15 or 20% of the facility beds to this kind of patient, you will find that the success rate relative to maintaining a level of care will be much easier to achieve.

STATEMENT OF IRA SCHNEIDER

Mr. SCHNEIDER. Thank you, Congressman.

The common problem that virtually all Alzheimer's patients and their families face is how do they pay for medical care. Sooner or later they are going to end up on Medicaid, and I urge the Congressmen to change the Medicaid laws as they pertain to the counting of spousal income and resources. This is commonly known as the "Deeming Law." It is set for in 42 CFR section 435.7223. The deeming laws deny the individual patients the choice of remaining at home or being institutionalized.

As ludicrous as it sounds, the Medicaid law encourages patients to enter nursing homes rather than have home health care. How does it do this? The law says that for as long as the spouses live together and for the first 1 month they are living apart, the income and resources of both spouses, husband and wife, are deemed available in figuring the eligibility for Medicaid of either spouse. However, if the patient is institutionalized, if we put him in a nursing home and he stays there over 1 month's time, the income and resources of the noninstitutionalized spouse are no longer deemed available. This has been upheld in the highest court of this Nation on the grounds of cost effectiveness and, Congressmen, I say this rationale is certainly hog wash. It is not cost effective. It encourages people to place their spouses into a nursing home at a much greater expense to the taxpayer than if they just stayed at home where they would get the better treatment that they need at home, if only the Medicaid Program didn't count the income and resources of the spouse. And I have set forth a hypothetical example, and while it is hypothetical, it is based in fact because as an attorney in this field, I have encountered it thousands of times.

We have a husband and wife, John and Mary, and they are 80 years old, for example, and John has Alzheimer's and he is going down the tubes rapidly. He is confused, but the longer he stays home in familiar surroundings, the longer he is going to have what few mental wits he still has. And this is commonly known. Whenever he is out of the home and he is hospitalized, he is extremely agitated and he turns mean and hostile. His wife would like to keep him home, but John requires extensive home health care aids and the estimated cost at this time in this area is $2,400 a month. If John stays at home, he and his wife will have to exhaust all of their resources before they will qualify for Medicaid. If John stays at home after they have exhausted all of their resources, the Medicaid Program will allow the husband and wife a total of $620 per month in income. The rest of their income must be spent down—this is known as the "Spend-Down Program"—on medical bills. The alternative is to place John in a nursing home at which time John spends his resources, but Mary can keep her resources. So if all of their assets are joint, we only have to spend half the money. John's income is paid to the nursing home. He is allowed $40 a month, as a chronic care allowance. Mary's income is not deemed available, no matter how high Mary's income is or how small it is; it is not deemed available. If Mary is left with insufficient income upon which to live, she has the option of suing John in Family Court, and the Family Court will ordinarily order John to pay for

Mary's care. So all of the laws here are geared to putting John in this nursing home. And I tell you, this is absurd.

Now, Mary has one alternative. She can terminate the marriage, a divorce. That is Mary's out. Now, the irony of the "Deeming Law" is that if the patients want to stay married and reep the benefits of Medicaid, they have to live apart. But if they get a divorce, they can live together and get Medicaid.

I urge you to change this law, Congressmen. Thank you.

[The prepared statement of Mr. Schneider follows:]

PREPARED STATEMENT OF IRA S. SCHNEIDER

This testimony is offered to persuade Congress to alter the method by which spousal income and resources are counted under the Medicaid program. The present method, commonly known as the "deeming laws" are set forth in 42 C.F.R. Section 453.723. The "deeming laws" deny chronically ill patients the financial freedom of choosing home health care as an alternative to institutionalization.

The "deeming laws" provide that for so long as a patient resides with his/her spouse, the income and resources of both patient and spouse are "deemed available" in determining the patient's eligibility for Medicaid. However, if the patient has been institutionalized for one month or longer, and remains institutionalized, the income and resources of the non-institutionalized spouse may not be deemed available in determining the patient's eligibility for Medicaid.

This discriminatory treatment of institutionalized and non-institutionalized patients has been held to be constitutional by the U.S. Supreme Court upon the grounds that there exists a rational legislative purpose. [Schweiker v. Gray Panthers, 101 S.Ct. 2633 (1981)]. The rationale is:

> "Sound principles of administration confirm our view that Congress authorized 'deeming' of income between spouses. The administration of public assistance based on the use of a formula is not inherently arbitrary. CF. Weinberger v. Salfi, 422 U.S. 749, 781, 782, 784, 95 S.Ct. 2457, 2474, 2475, 2476, 45 L.Ed.2d 522 (1975). There are limited resources to spend on welfare. To require individual determinations of need would mandate costly factfinding procedures that would dissipate resources that could have been spent on the needy. Id., at 784, 95 S.Ct., at 2476. Sometimes, of course, Congress has required individualized findings of fact. In this case, however, the Act and legislative history make clear that Congress approved some 'deeming' of income between individuals and their spouses, at least where States had enacted rules to this effect before 1972." 101 S.Ct. at 2642.

The absurdity of this discrimination and the Court's rationale is manifest when applied to chronically ill individuals who prefer to be treated at home in the presence of their families.

The following example typifies the dilemma that chronically ill patients and their spouses face as a result of the application of the "deeming laws":

John and Mary are each 80 years old. John is suffering from Alzheimer's disease. He's deteriorating rapidly. He is quite confused, but

the presence of his wife and familiar surroundings are beneficial to him. On the occasions when John has been hospitalized, he's been extremely agitated and hostile. Mary would prefer to keep John at home, but John requires extensive home health care assistance. The estimated cost is $2,400 per month for a 24-hour home health aide. Mary and John's life savings consist of $50,000 in a joint bank account and their house. John receives Social Security of $800 per month; Mary's Social Security is $400 per month.

In order for John to qualify for Medicaid for home health care, both Mary and John would first have to exhaust their entire life savings on medical bills. In New York, they would be allowed to retain $4,600, plus two $1,500 burial allowances. Then, they would have to "spend-down" their income of $1,200 per month to the Medicaid level. (In New York, this is $620 per month). In other words, they would have to spend $580 per month on medical bills after exhausting their life savings and only then would the balance of the medical bills be covered under Medicaid. John and Mary would be forced to exist on $620 per month for all non-medical expenses: food, fuel, real estate taxes, clothing, transportation, insurance, utilities (entertainment would not be affordable).

However, if John were committed to a nursing home, only one-half of the $50,000 in joint savings would have to be expended. John's income would be spent on the nursing home bill except for a chronic care allowance ($40 per month in New York) and Mary would be left with her Social Security of $400 per month. If John is institutionalized, Mary could sue John for support in Family Court and provided she can document the need for support, the Court may be expected to order John to pay Mary an amount sufficient to pay her expenses.

From a strictly financial viewpoint, it would be advantageous for Mary to place John in a nursing home, exhaust his one-half share of the joint savings account, and then apply for Medicaid. Mary would be left with her one-half of the savings and could seek additional support in Family Court. The alternative of keeping John at home with home health aides is foreclosed by the "deeming laws". If John remains at home, Mary faces certain financial ruin.

Mary's only other alternative if John is to remain at home with home health care is obtaining a divorce.

Since only a spouse's income and resources are deemed available, if

the marriage is terminated by divorce or annulment, Mary's income and resources are no longer counted.

The irony of this legislative quagmire is that if John and Mary remain married, they have to live apart for John to obtain Medicaid. Only if they're divorced can they live together and obtain needed medical assistance.

The problem is accentuated in "non-spenddown" States (e.g. Florida). In Florida, even if Mary and John spent their entire $50,000, John would not qualify for Medicaid for home health care because the combined marital income exceeds the SSI allowance for a couple. However, if John is institutionalized, only his income is counted and he would qualify for Medicaid. Again, by placing John in a nursing home, Mary would save her one-half of the joint savings.

The deeming laws compel institutionalization at a far greater expense to the taxpayer. The deeming laws divide families who would rather stay together. The deeming laws are discriminatory and dangerous to the basic fabric of our society: the family. The deeming laws should be changed.

DATED: May 29, 1986

IRA S. SCHNEIDER

Mr. DOWNEY. Thank you.

The committee will recess for 5 minutes, and I stress for 5 minutes, because the gavel will come down in 5 minutes and the remaining congressional people will ask witnesses of this panel questions and inquire of them, and then the expert panel will proceed immediately thereafter.

We will recess for 5 minutes.

[Recess.]

Mr. MANTON. We are going to resume the hearing by the Select Committee on Aging. If everybody will be kind enough to take their seats, we will get started again.

Before we get to our next panel of experts, I believe we have a few questions of the first panel.

Mr. Mrazek?

Mr. MRAZEK. Thank you, Mr. Chairman.

I just want to commend the members of this panel for some very illuminating testimony and powerful testimony, in fact eloquent in describing the parameters of the problem. I would like to focus a couple of questions on the concept of residential versus day care.

We heard testimony to the effect that some patients in one of the stages of Alzheimer's can become paranoic, physically confrontational at times, indulge in some antisocial behavior, largely, perhaps, because of a change in their surroundings which they find it difficult to deal with.

I am wondering at what point day care ceases to provide—what are the parameters for when day care is going to provide a useful and constructive setting for a family that has to confront this disease?

Perhaps anyone who wants to speak to that?

Ms. TOLLE. Besides being the president of ADRDA, Nassau-Suffolk County, I am also the director of the club, an Alzheimer's day program located in Lynnbrook, which is sponsored by Penninsula Counseling Center, funded by Nassau County Department of Senior Citizens Affairs. Our program has been open 2 years. We are a social model day care program, open 4 days a week. Our people that come to our program with Alzheimer's disease, some are high functioning, some are moderate functioning, and we have many that are low functioning and need total care. Our people, when they are withdrawn from our program, do go straight into nursing homes. It is difficult to say how long do you keep somebody in a program. It depends whether you are providing respite to the family or providing an environment for the person with Alzheimer's disease.

There are many times that in our program, and I am sure Paul can say the same thing, we do keep people in the programs longer than they actually do get benefits from the program, because we are providing respite for the families because there is no other place for them to turn, especially with the waiting list for the nursing homes. So that there are times the people are in a day care program long after they are benefiting by it, but there are no other alternatives for their care at that time.

Dr. STEFFENS. May I add to that? Well, go ahead.

Ms. WHITE. I would like to add that I just recently did research on seven of our day care programs which are operating just in Suf-

folk County. We need many more, and one of the biggest problems is the case of transportation because of the physical layout of our community. However, my question concerned whether or not people felt they were assisted by having the person in day care, or whether they had considered institutionalization. Ninty-nine percent said they did consider either institutionalization or home care, but found day care did help to assist them. They felt that longer hours were needed and would be helpful; that weekends would also be a help to them. But even with the limited hours, they found that this did help to delay institutionalization of the patient and did allow them to either continue work or give them the respite they needed.

Dr. STEFFENS. May I add to that? I agree with Ms. White. With the Alzheimer's that we have in our medical model—I want to mention there are many wonderful social models in Nassau and Suffolk County—but in our medical model, we find that we do give respite basically to the family. When it reaches the point that the 8 or 10 hours of respite we do give the family is not sufficient, then they have to consider institutionalization. But there is no question about it, I feel very strongly about it. The medical model day care is slowing down the admission into the institution itself, and it will continue.

I happen to be a member of the Health Systems Agency as well, and we probably have about five more on the managing board in Nassau and Suffolk County that are strictly medical models. We will be able to take care of these kind of "registrants," we call them, by State regulation.

Mr. ARFIN. When a family calls and they describe their circumstances with a relative with Alzheimer's disease, we usually are able to say, "Let's try it out. Let's see," because there is no hard and fast rules. Continency is a variable that we have to look at. Accidents we can cope with, but if it is ongoing, we can't. Agitation, the extent to which there is agitation, whether we can manage it or not in an effective and caring way. And the extent of straying. There is all kinds of reasons for straying. How often does it happen? When it happens? Every minute, all day long for 8 hours, we can't do it.

So, those are three main variables for us. I guess because we have little children in our facility also, we have to be particularly sensitive to the comfort level of the parents of the children, but on the other hand, as we touched on before, oftentimes the children being nearby provides a sense of comfort and fond reminiscences that are salutory for the Alzheimer's patients.

Mr. MRAZEK. When a patient shows any sign of antisocial behavior, do they have to be essentially removed from the program?

Mr. ARFIN. What usually happens is there is some shoving, there is some movements, and staff—first, you have to see how your staff feels and their ability to cope, and that becomes a barometer of whether you are going to be able to manage it. Yes, if that becomes too frequent, we are not able to provide a closed-door setting and don't want to. I think there is a need for it, but we have defined our parameters as being an open setting, and part of that is because we also have children.

Mr. MRAZEK. Is it fair to say that a day-care center is really only an effective approach so long as a patient has periods of lucidity, recognizes their loved ones——

Mr. ARFIN. No, not necessarily. We have Alzheimer's patients that are 5, 10 years into the illness and do not recognize their spouses at all or very infrequently, and they are coming to the center 5 days a week.

Mr. MRAZEK. And they are living with a spouse they have no recognition of?

Mr. ARFIN. Very little. Just episodically.

Ms. KENNEDY. May I speak to that fact, Congressman Mrazek spoke of?

Families for whom there is no day care possibility for perhaps facts of geographical location, transportation and whatever, and you asked whether it is considered feasible or when does a person move into a nursing home: The course of the disease is not so regular. It depends on the availability of the capacity of the family to be able to take care of the total responsibility. Often times it is incontinence, often times it is loss of speech, often times it is the turmoil in the home of having to keep everything locked, hitched, closed and so on, the destructiveness and so on.

The most important thing is that it is not just not recognition, but the family feels that they have lost the helpmate that they knew, but they still have to keep that body present, and the guilt and the worry of having to, say, institutionalize, plus the expense—because many families are not aware of the alternatives even though they are few, but feel it would drain their life savings and home and so on. Some families do keep the Alzheimer's person even beyond the paranoid behavior, even beyond the nonrecognition, so that people have said "This is not my spouse; it is a person that I have an obligation to care for." But it really depends on when they have given up and said, "I can no longer cope with this." Then it is the time.

Mr. MRAZEK. Mr. Schneider was the only one to suggest or recommend specific action by Congress. Aside from the clinical questions which we will be dealing with in regard to the panel of doctors, are there directions that any of you would see as being fruitful for Congress as it relates to the information available to families dealing with this kind of crises? Do we need some type of public—additional public education program at the Federal level which would provide a clearinghouse of information of alternative sources, or is that something that exists but has to be improved; or any other types of recommendations?

Ms. KENNEDY. The first piece, I would say, would be restructuring of our health care financing.

Dr. STEFFENS. Yes.

Ms. KENNEDY. Restructuring not so much Medicare, but total financing of health care and not just for elders.

Dr. STEFFENS. Bob, may I say something? I feel Congress should somehow make sure that Medicare begins to cover some of these people in day care, both medical and social problems.

Ms. KENNEDY. And home care.

Dr. STEFFENS. And home care. There is either no or minimal coverage. For example, if I give a patient an OT treatment or, let's

say, a PT treatment, physical therapy, that might be covered, but occupational therapy is not. It is very important that these people be taught how to function in a daily living situation and that is not covered under Medicare while physical therapy is.

In reality, what Medicare is paying is restorative and with these people there is really very little potential, restorative potential.

Mr. MRAZEK. By the same token, for a degenerative disease, what is the value of occupational therapy if, in fact, the situation only becomes worse?

Dr. STEFFENS. If you can teach the individual how to function to some degree at home when they are out of the day care center with occupational therapy, you are going to minimize that regressive downward movement.

Ms. TOLLE. Another thing: This is something that doesn't even fall under occupational therapy or restorative therapy.

We know, based on what people working in day care programs and families have told us, that on days that their family members are in the day care setting, they sleep better at night, they are less agitated, they are more social at home. These are benefits to the family that haven't been measured yet and hopefully they will be, but at this point they are things that are very important to help the family cope at home. For that reason, the day care centers are extremely important.

There are medications that can be given to help with the agitation and other problems that cause management problems of a person with Alzheimer's disease, but here are programs that people come to, and just from being in the programs and enjoying themselves and being in a relaxed environment during the day, they are going home with benefits not only to themselves, but to the family, the care givers that are caring for them.

It is virtually impossible for these families with financial situations the way they are now to pay out for a day care center on a daily basis. Our center, since it is on a grant, there is no fee. If they had to pay a fee it would be $35 a day for that, home health care, $7 or $8 a day for intermittent care. Then you have regular doctor visits. Then you have to wait until you can get into a nursing home and start paying out $4,000 a month for that. Most of the nursing homes are asking 3 to 6 months in advance for private patients who can afford that. Most of our families cannot afford that kind of money. They are really in a pickle right now. Public awareness is extremely important and I think it has to come from the Federal Government.

Home health agencies and the requirements for home health aides and the way they are trained is an extremely important issue. Home health aides are going into homes very untrained to take care of our family members. That is an extremely important point to be addressed. I don't know if it is going to be on a State basis or national basis.

Ms. WHITE. I would like, if I may, to add something.

You are talking about OT, and actually the patient is not going to benefit, not going to be restorative. Nevertheless, in the research that I did, the majority of respondents said the patients' day care became their occupation. That they started to almost feel like they were going to work. "I have to go to work today. I have to do this."

I think that benefit right there, giving dignity back to that person regardless of whether—what they have done occupationally at the day care center, it still replaced what they did in their normal life and helped to prolong this feeling.

Mr. SCHNEIDER. If I may, there is a part of the current program under the Social Security Act, from Medicare, it is the Hospice Program. It is due to expire this year. Now, the Hospice Program is very helpful for a terminally ill patient. I would urge Congress to renew the Hospice Program and not only to renew it, but to extend it beyond terminally ill, so that it encompasses Alzheimer's patients who are not, "terminally ill." They are not expected to die in 6 month's time and yet they need this hospice care at home.

Ms. KENNEDY. The crux here is that Alzheimer's is considered a chronic disease and, therefore, it is not possible for rehabilitation. Some of the hospice programs will address only the accute diseases. Am I correct?

Mr. SCHNEIDER. That's correct.

Under the current law, the Hospice Program is only available for terminally ill patients.

Ms. KENNEDY. But terminally ill accute diseases.

Mr. SCHNEIDER. You have to die in 6 months. A doctor has to certify that you will die in 6 months. Most Alzheimer's patients, you can't say that. So, it is not available. Even if it were, it's expiring at the end of August and I haven't heard anything about it being renewed, unless I haven't been reading the right newspapers, perhaps.

Mr. MRAZEK. It's fair to say we have a budget crisis in place right now in Washington that no one is in a position to forecast the result of. So, I am not in a position—I don't know about Congressman Manton and I don't think anyone at this point in Washington or out of Washington is in the position to give an answer to that question, to what extent hospice care will be continued. I am confident we will see the programs continued, whether to the extent they should be, I don't know.

One final question relating to something you spoke about earlier, that relates to the patients being covered by Medicaid and why, in fact, would it only be patients covered by Medicaid that would be involved with the day care program?

Dr. STEFFENS. Under the Lombardi bill, it's Tallon and Lombardi, State of New York, that clearly stipulates we are only to charge, under the medical model day-care center, the Medicaid rate the State gives us. We take anyone. If a private wants to come in, they will pay the private rate. Very rarely will you find a private family is willing to pay $65 a day. So right now, 100 percent of our population is Medicaid.

Incidentally, social models are not reimbursable while medical models are 100 percent reimbursable under the Medicaid Program.

Ms. KENNEDY. But you have to be poor. You have to be so poor.

Dr. STEFFENS. You have to talk to Mr. Schneider over here to tell you how to get on Medicaid. And he's done that, incidentally, successfully with at least 25, 30 of my people. I refer many to him.

Mr. MANTON. There are a lot of questions. Most of the questions that have been submitted are for our scientific panel. I think, in the interest of moving along, I am sure that we would have many

more questions for panel No. 1, but I think it is time for us to perhaps indicate that whatever questions we might have, we might submit in writing and that the panelists answer us in writing, if possible.

We thank you very much for your very informative testimony.

I would like to note for the record, I understand my colleague, Mr. Downey, simply introduced the panelists by name. But their bios will be made part of the official record of today's proceedings.

Dr. Henn, I think you mentioned you had a commitment to get to, so we will hear from Dr. Fitz Henn, chairman, department of psychiatry and behavioral sciences, Stony Brook University Hospital, as a lead-off witness.

Dr. HENN. Thank you.

PANEL 2, CONSISTING OF DR. FRITZ HENN, CHAIRMAN, DEPARTMENT OF PSYCHIATRY AND BEHAVIORAL SCIENCES, STONY BROOK UNIVERSITY HOSPITAL, STONEY BROOK, NY; DR. MAYNARD MAKMAN, PROFESSOR OF BIOCHEMISTRY AND MOLECULAR PHARMOCOLOGY, ALBERT EINSTEIN COLLEGE OF MEDICINE, BRONX NY; DR. RICHARD C. MOHNS, ASSISTANT DIRECTOR, ALZHEIMER'S DISEASE RESEARCH CENTER, MOUNT SINAI SCHOOL OF MEDICINE, BRONX, NY; DR. PAUL HELMS, ASSISTANT PROFESSOR OF PSYCHIATRY, DIRECTOR, STONY BROOK UNIVERSITY HOSPITAL ALZHEIMER'S DISEASE PROGRAM; AND DR. RONALD M. LAZAR, NEUROPSYCHOLOGIST, SUNY HEALTH SCIENCES CENTER OF BROOKLYN, NY

STATEMENT OF DR. FRITZ HENN

Dr. HENN. Thank you very much. I appreciate the opportunity to come here and talk to you. Also, for the sake of brevity and maybe even clarity, I will deviate from my written remarks.

Mr. MANTON. Without objection, your written remarks will be made part of the record.

Dr. HENN. Thank you.

First, I would like to compliment the social panel. I think they made it crystal clear what the needs are. I think the toll Alzheimer's takes in its distribution have been very clear. The question really is how can we approach it?

What I would like to do is briefly tell you what we are trying to do at Stony Brook, and not particularly to be parochial, because I think my colleagues at Einstein and Mount Sinai will tell you much the same thing is going on, but to focus on the areas where we think we could use help from both the Federal and State Governments.

There are two broad areas of research that I think we have to undertake in this disease. The first is how can we better treat people. We effectively have no treatment at this point. The disease progresses at its own rate and there is very little we can do to alter it. You have heard about the range of care that has been provided under various guises, which includes home health aides, crisis teams going into the family, day care, respite care for over night, on to institutional care. I think one of the first things we have to try to do is to find a way to organize this system so that patients

progress through it in a logical fashion and also manage to stay in the context of their families as long as possible.

What we are trying to do is work with both the State of New York and with private industry to develop some models. I don't know if any of them are particularly original, but they would encompass the daycare programs; they would encompass crisis intervention teams that would go into the home early; and they would encompass respite care where patients whose families are struggling with them would have the opportunity to have a night or two nights or a weekend off, basically, to design facilities that better meet the needs of Alzheimer's patients.

When one goes to many nursing homes today, one finds the Alzheimer's patients sedated, sitting in geri-chairs, relatively confined. In fact, very, very little wrong with them medically, and this is done because of the paranoia that was brought out, because of the occasionally unpredictable behavior and because of the almost 100 percent wandering behavior. What we would like to try and do are develop some nursing home models and daycare models that have enclosed perimeters, but allow some freedom. I think the daycare model is extremely important because of the dignity it gives the patient and rest it gives the family, but there are times when it just can't provide enough and you have to move on to a nursing home.

One of the things we are interested in is trying to redefine nursing home facilities specifically for people with cognitive problems. In order to do this, we worked with the State of New York and they are going to build a nursing home, veterans home, with Federal dollars and State dollars on the campus of Stony Brook. We have already initiated talks with the architects to try and design a wing of that home specifically for cognitively impaired patients. Namely, we hope the halls won't be long and essentially faceless with identical rooms. Rather, the architecture will be so designed that there will be distinctive areas and the patients will recognize them because they have memory problems. The perimeter will be enclosed so we don't have to keep people in geri-chairs. These kinds of facilities will help us with care.

What do we need from you under these circumstances? First, some money for evaluative research. We don't know at this point which of these programs will stabilize and maintain the patient best. And we need some help through the National Institute of Aging to evaluate these programs. Such help is already available and we owe a lot to you for that and I think it should stay in exactly the form it is, namely competitive peer review programs. I think we need a little more along these lines.

The next area I would like to briefly talk about are the major research goals. The fact of the matter is that no matter what kind of a care system we are going to provide, it is going to be too costly and it is going to continue to grow and eat up a major part of the budget, the health care budget of this country until we figure out something about the etiology of this illness, and find a way to either stop it or treat it. In order to do that, I think we need support for basic science research, and I think, if you will allow me, I will just outline briefly where we are in that area.

There are several themes that run through Alzheimer's research. The first, which Dr. Makman will probably tell you a lot more

about, involves neurotransmitter studies. It turns out there clearly are a group of cells in the central nervous system that die because of this disease that use the neuraltransmitter acetylcholine, involved in memory. Our understanding of how to replace this loss function might help us develop some treatment modalities that might help retain memory.

One of the other major areas are the areas of toxins. Are there toxins that cause the disorder? My own hunch is that's probably not the case, but we need further looks into the kinds of toxic exposures patients have had and whether this really plays a role.

The last area we have to look at are infectious agents. It is pretty clear that some form of dementia, Creutzfeldt-Jakob, is one, are caused by infections. I think the area of investigation of slow viruses will become critical and paramount.

At Stony Brook we are trying to attempt to look at all these areas in families that have genetic predisposition. Genetics play an important role in this illness, and we need research dollars. I think the bottom line from the academic community is really very simple. We need support at the basic biological science level, and we have to focus some attention on this. Just as AIDS has focused attention, I think we need that kind of attention for Alzheimer's disease.

Thank you.

Mr. MANTON. Dr. Henn, I know you have to leave, but my colleague, Mr. Mrazek, has one question for you.

Dr. HENN. Sure. I can stay until about 3:30 if you want to go through.

Mr. MANTON. OK.

[The prepared statement of Dr. Henn follows:]

PREPARED STATEMENT OF DR. FRITZ A. HENN

The Honorable Robert J. Mrazek
143 Main Street
Huntington, N.Y. 11743

Dear Mr. Mrazek:

Alzheimer's disease currently fills about one third of all nursing home beds nationally, increases in incidence with age and is not currently curable. Those facts set the stage for what clearly is emerging as a major health care crisis in the 1990's. Given also, that people with dementia are having real difficulty getting appropriate care and even getting into nursing homes, we begin to see the cost of this problem to the people in Long Island and the nation. At University Hospital on the Stony Brook Campus we are attempting to start a comprehensive program to study dementia.

There are two phases to the program. One aimed at the development of better services for people and families afflicted with dementia and the other aimed at research into the cause and hopefully to the cure of the conditions. The care model we seek to develop recognizes that traditional nursing home care is somewhat inappropriate for people with cognitive not physical impairments. Often the best care is provided by the families of patients, but at an enormous cost. The care becomes consuming and eventually almost an impossible burden for the family, as the patient cannot be left alone, wanders at night and cannot stick with any tasks without help or supervision.

Our goal is to develop a model beginning with a careful diagnostic evaluation aimed at finding all the correctable causes of dementia and then working with the family to design a care program, if possible in the home. To make this work consulting teams should make home visits, a program of day care and evening care should be available and overnight respite care should be available to the family. When institutional placement is needed we feel a facility designed for cognitive deficits would have programs and architecture which would avoid overmedication and more sitting in gerry chairs. Such a facility would have a secure perimeter so patients could move about without fear of getting out and getting lost and would not have long faceless are currently working at three levels to develop such programs and to evaluate the effect of such care on the rate of progression of the illness. Attempts to build a private facility offering day and evening care and respite care are underway. Also efforts have begun to work with the Office of Mental Health of the State of New York to begin a comprehensive geriatric program using parts of the State Hospital complex at Central Islip. Finally the State Veterans Home to be built on the Stony Brook Campus will have a wing designed specifically for patients with Alzheimer's disease and other dementias.

These efforts are necessary to deal with the problems we currently see among the elderly on Long Island. However, as I mentioned at the outset there is no viable treatment or cure for Alzheimer's disease. As long as this situation persists we will be fighting a losing battle in providing services. For as our population ages we will see more and more cases. The only hope is fundamental research into the cause and cure of the disorder. Such research has made remarkable advances in the last years, but is still not at the point of understanding the disorder. There are three threads of research which have evolved and through them it appears that we will have a chance at unraveling the origins of this disorder. In brief, there are studies of neurotransmitter abnormalities in Alzheimer's. Neurotransmitters are the chemical signals which communicate between nerve cells and there are a host of them involved in brain function. Several groups including Peter Davis, now of Einstein and the Johns Hopkins group have demonstrated that the most significant neurochemical change in Alzheimer's is a drop in acetylcholine, one of the major neurotransmitters. This drop is due to cell death, cells which make Acetylcholine and one group of these cells in the basal forebrain is particularly hard hit. Other transmitters are

also decreased and scattered cell death is a pathological feature of Alzheimer's disease. These areas, have characteristic plaques and tangles, areas of disorganized cellular debris, and the question is why. Two major possibilities have been suggested and are not exclusive. The first involves an infectious agent either a virus or the suggestion of a new agent, the prion. Though the prion has slipped off the front page of the press the possibility of some type of viral infection remains. A rare form of dementia, Creutzfeldt-Jakob disease, which is rapidly progressive and fatal usually clearly appears to have a slow viral etiology. By analogy many investigators feel a viral etiology is the best explanation for the scattered pathological changes seen in Alzheimer's disease. Along with this we must consider the genetic factors which appear to play a role in the disease. Risk for Alzheimer's disease is higher for family members where one member already has the disease and there is clear association between Alzheimer's disease and Downs Syndrome or Trisomy 21 a defect in the expression of chromosome 21. These facts, suggest that some inherited factors, perhaps on chromosome 21 may play a role in the illness.

These three areas of study are all potentially interrelated and we propose to establish laboratories at Stony Brook aimed at using populations at genetic risk to study both the viral and genetic hypothesis. The use of molecular biology to probe for the defect holds great promise and we are developing a laboratory with this expertise. Currently we are developing a library of C-DNA probes for all the CNS filament proteins, those proteins which form the characteristic pathological lesions of Alzheimer's disease. We hope that with continued federal, state and private support we can help find solutions to this devastating disease.

Thanks for the opportunity to share our plans and encourage continued federal support for research in this vital area.

Sincerely,

Fritz A. Henn

Fritz A. Henn, Ph.D., M.D.
Professor and Chairman

STATEMENT OF DR. MAYNARD MAKMAN

Dr. MAKMAN. Thank you.

I appreciate the opportunity afforded me by Congressman Mrazek and the committee to appear here and to sort of represent, in a way, the basic sciences and the way in which basic neuroscience research can correlate, integrate with clinical work in trying to somehow learn more about this terrible disease and what we can do about it in terms of curing it and treating it. It is quite an effort, but tremendous more needs to be accomplished in this area.

Basically neuroscience and related research have already made contributions, as has been alluded to, to the understanding of the nature of Alzheimer's disease. At this point these indicate the potential of further research for aiding the diagnosis and treatment and understanding the cause of Alzheimer's.

Our own research, for example, really is concerned with understanding brain neurotransmitter symptoms that are directly or indirectly altered in patients with Alzheimer's disease. We have been interested in the biochemistry of aging for maybe more than 15 years at this point, and others at our institution have long-standing interest in this as well.

We have an interest in finding out what are the important changes that occur in the brain with age. This includes not only the biochemical changes, but the impact these have on brain function. We think these are really very important, really, directly for the Alzheimer's patient, because in Alzheimer's disease it is the brain of an elderly individual that is affected generally and the responsiveness to treatment is dependent on the status of that brain more so than that of a younger individual. Also, the concomitant diseases present in this population need to be taken into account and considered really in the research as well that we are doing in Alzheimer's disease.

The best characterized biochemical changes found to occur in the brain of Alzheimer's patients are those involving acetylcholine, just mentioned, and also the neuropeptide somatostatin reductions in Alzheimer's brains of choline acetyltranferase, the enzyme that makes acetylcholine, and also of somatostatin.

Mr. MRAZEK. Excuse me, Doctor, did you start speaking in a different language a few minutes ago? That is the problem with Members of Congress. I am sure the audience was following you very well.

Mr. MANTON. As a matter of equal time, Members of Congress also have a strange language they talk that the general public doesn't understand from time to time.

Dr. MAKMAN. I will try to make it clear.

Because of these neurochemical changes that occur, we feel that if we can learn more about the basic mechanisms involved, we will get an idea of the drugs that can influence these systems and then be used, indeed, to treat Alzheimer's disease. One example of this, in fact—now I am deviating from my written testimony—is the drugs that have been used which actually inhibit the degradation of acetylcholine, so there is more acetylcholine. This is in a sense a way to get replacement therapy in Alzheimer's similar to that which is done, well understood, in Parkinsonism, to replace dopa-

mine. It should be said that while this is an interesting possibility, and you can show experimentally some improvement, much more needs to be done in this area. This has not yet been really successful in clinically improving the patients to a really meaningful level. But at least it shows where the future may go, and that there are possibilities.

Another tact being taken, because these nerves degenerate, is to try to find out why and how one might perhaps make them regenerate or stop the degeneration. For example, Dr. Kessler at our institution is purifying the growth factor that may help cholinergic neurons either to be maintained or regenerate. This is another important tactic.

Still another tactic being taken by Dr. Peter Davis at our institution is to look for specific changes in the brain, specific proteins in Alzheimer's patients that are changed or are different. He has identified one such protein, which if you will pardon my giving a name, he called Alz-50 antigen. In any case, apart from the name of this protein, it does exist in Alzheimer's patients and is either very low or absent in normal patients. It is found in regions of the brain where the disease is present, at least it is concentrated there. This may be a clue to the nature of the disease and it also, if one can detect it in the patients, may be a way of diagnosis and may be even getting a selective diagnosis for Alzheimer's, really a major and important problem in this area.

I say this is really just the beginning. We need to look for proteins, other mechanisms that are changed. This is really essential if we are going to eventually have a reasonable treatment for the disease and, certainly, if we are going to discover its etiology and find a way to cure it.

Mr. MANTON. Thank you.

[The prepared statement of Dr. Makman follows:]

PREPARED STATEMENT OF MAYNARD H. MAKMAN, MD.

Alzheimer's disease is the most common form of senile dementia, a condition affecting over 4% of Americans over the age of 65. Alzheimer's disease will become an even greater health problem as the proportion of our population that is elderly continues to increase. While much more remains to be accomplished, basic neuroscience and related biomedical research investigations have already made important contributions to our understanding of the nature of Alzheimer's disease. These contributions indicate the potential of further research for aiding the diagnosis and treatment as well as understanding the cause and possible cure of the disease.

Our own research is concerned with understanding brain neurotransmitter systems that are directly or indirectly altered in patients with Alzheimer's disease. Also, we have a long standing interest in finding out what are the important changes that occur normally in the brain with age. This includes not only the biochemical changes themselves but the impact of these changes on brain function and on the response to drugs that might be used in therapy. We believe these studies to be very important for the Alzheimer patient, since Alzheimer's disease is an affliction of the brain of an elderly individual and the effectiveness of treatment will be dependent on the status and responsiveness of that brain rather than that of a younger individual.

The best characterized biochemical changes found to occur in the brains of Alzheimer patients are those involving the neurotransmitter, acetylcholine, and the neuropeptide, somatostatin. Reductions in Alzheimer brains of choline acetyltransferase, the enzyme that synthesizes acetylcholine, and of somatostatin have been found by a number of investigators, including most notably, Dr. Peter Davies of our own Institution. These changes include loss of acetylcholine-containing neurons innervating regions of the cerebral cortex, as well as loss of somatostatin that is normally present in separate neurons in the cortex. Some of our studies, carried out in experimental animals, concern the influence of transmitters (such as acetylcholine and dopamine) and of related psychoactive drugs on somatostatin-containing neurons in the cortex. We find, for example, that dopamine or drugs that stimulate dopamine receptors behave like acetylcholine in that they stimulate release of somatostatin in cortex. These and related studies may eventually provide new approaches for correcting or treating the neurochemical deficits found in Alzheimer's disease.

Our studies of normal brain aging in experimental animals have revealed selective changes in dopamine neurons that help to explain changes in drug responsiveness and in worsening of diseases such as parkinsonism that occur in elderly men and women. These studies may be relevant to Alzheimer's disease in that a subgroup of afflicted individuals may show deficits in dopamine and other amines, in addition to the deficits in acetylcholine mentioned previously. It is of interest in this regard that etiological, and possibly other relationships between Alzheimer's disease and parkinsonism have been suggested. We are also investigating the reciprocal effects of drugs that influence acetylcholine and those that influence other transmitters such as dopamine. This is of critical importance in developing more selective and effective drug regimens to correct for cholinergic and related deficits in Alzheimer's disease. This is clearly an area where future research is needed to yield clinically effective drugs.

Much attention has been given to the cholinergic loss in Alzheimer's disease since that loss best explains the memory and other changes seen clinically. One important area of research of a number of investigators is that being devoted to obtaining a better understanding of the biochemistry and the cell biology of cholinergic neurons. Included are studies of growth factors and other substances that may influence growth, survival or regeneration of cholinergic neurons. In other studies, investigators have attempted to develop an animal model of Alzheimer's disease by producing selective lesions of the appropriate cholinergic neurons in rodents or primates. The development of such an animal model is important in that it will provide a system for finding and evaluating better therapeutic approaches for treatment of the human disease.

A different approach has been taken recently by Dr. Peter Davies's group at Albert Einstein with the long term objectives of elucidating the etiology of Alzheimer's and also of providing new tools for diagnosis. These investigators have utilized monoclonal antibody technique to identify a protein "Alz-50 antigen," that is present in Alzheimer's but nearly absent in normal brain. The Alz-50 antigen is concentrated in Alzheimer brain in regions containing neurofibrillary tangles characteristic of the disease. It is also in some neurons that appear to be normal. Hence, the Alz-50 antigen may already be present at an early stage of the disease. This will be of particular diagnostic importance if it turns out that the antigen can be detected in the cerebrospinal fluid of patients. Elucidating the nature of the Alz-50 antigen as well as other Alzheimer-specific proteins yet to be discovered may help elucidate the cause of the disease and/or some of the unique mechanisms involved in the disease process.

It is hoped that these examples will make evident the varied and important contributions that basic neurobiological and neurochemical investigations have and will continue to make to the diagnosis and treatment and ultimately to the eradication of Alzheimer's disease. There remains many possibilities as to the nature of the disease, as well as various avenues to be explored for treatment. It is necessary now to utilize the major recent advances in the neurosciences and related disciplines to follow up on the important clues we have concerning this devastating disease, in order to most effectively treat it, and if possible to eradicate it.

Dr. Maynard H. Makman
Professor of Biochemistry and
Molecular Pharmacology
Albert Einstein College of Medicine

Mr. MANTON. Dr. Mohs?

STATEMENT OF DR. RICHARD C. MOHS

Dr. MOHS. Thank you, Mr. Chairman.

If there is no objection, I will deviate.

Mr. MANTON. Let the record reflect all of the statements will be, without objection, inserted in the record verbatim, and that anybody that wants to summarize or ad lib is certainly welcome to do so.

Dr. MOHS. I am here today as a representative of one of the 10 Alzheimer's disease research centers which were authorized, fortunately, by Congress in 1984, and were established beginning in 1985 and on into 1986. These centers are funded by the National Institute on Aging and were given to 10 institutions around the United States that had active research programs in Alzheimer's disease. The purpose of these centers was to provide core resources to enable those institutions to expand their already existing research in a number of different areas.

Our center, which is located in the Mount Sinai Medical School in the Bronx Veteran's Hospital, had been engaged in research primarily in three different areas: One was the study of the longitudinal course of the disease in an effort to try to plot its course and determine whether or not there are subtypes of the disease. A second area which has been alluded to by the previous speakers, the development or testing of drug treatments that might alleviate some of the chemical abnormalities which have been defined in the brains of patients with Alzheimer's disease. The third was an attempt to develop some type of diagnostic marker.

As many people know, we do not have a definitive diagnostic test for Alzheimer's disease, and it is a major goal of research to try to develop such a test to tell us definitively who has the disease and who does not. As someone who has been involved in Alzheimer's disease research for about 10 years or more, I think we can see that there has been substantial progress made in our understanding of the disease. That, unfortunately, has not been the type of progress which has had a dramatic impact as far as the patients who actually have the disease and the families who have to take care of them are concerned, but I think it gives us a great deal of optimism about the future. Some of the work that I think is the most important that has already gone on and that is continuing is that, No. 1, we know a lot more now than we did previously about the neuropathology and neurochemistry—that is the brain changes characteristic of this disease. In spite of that fact, the diagnostic practices still vary around the country and there are cases where we can't be absolutely sure what the patient has. The National Institute of Aging has done a tremendous amount to standardize diagnostic practices around the country, and they are much better now than they used to be.

The methodology for evaluating treatments that are prepared for Alzheimer's disease is now much better established and understood than it used to be a few years ago. It is no longer difficult to get much concensus now-a-days about exactly what is a worthwhile thing to try, and exactly how to go about trying it. As previous

speakers have alluded to, we do not know the cause of Alzheimer's disease, but the indicated causes, I think, are pretty well agreed upon by a number of investigators and I think that the opportunity is available for us to proceed.

For the future, I think that we can be optimistic in the sense that there are lots of very important and interesting avenues to pursue. There are investigators who are in place who are willing to pursue them. And I would like to just outline five areas that I think are the most important ones to pursue and the most promising ones to pursue in the future.

First of all, studies of brain grafting. It is now well established in animals that brain cells can be transplanted into animals who have lesions of the brain, and that those cells when transplanted into the brain will, in fact, grow and develop as functionally normal cells. That work is being conducted not only in the United States, but at various places around the world. Although it has a long way to go before it comes out of the laboratory to the point where it might be clinically applicable, the relevance of that to the possibility of treating patients with a degenerative disease, with Alzheimer's disease, I think should be obvious to all of us.

Second is the study of genetic and other causes. It has been well known for a long time that some cases of Alzheimer's disease probably run in families. What is the role of genetic factors in more typical Alzheimer's disease is as yet unclear, primarily because it is a very late onset disease and studying the transmission through families of a disease that doesn't occur until the seventies or eighties is extremely difficult. Also, it is very clear that other factors may also interact with a person's genetic liability. Those are things Dr. Henn mentioned, such as a virus, infection, exposure to toxic agents, and so forth.

We know what some of those factors might be and we know something about how to look at them, but the actual studies will be long; they will be difficult; they will involve large numbers of people; and they will probably be expensive.

A third important area is the study of brain proteins, cystoskeletal abnormalities. It is now being understood there may be proteins, as the speaker from Albert Einstein described, there may be proteins that are unique in the brains of patients who have Alzheimer's disease. There may be things that are being produced into these brains that don't belong there and are the actual cause of the disease. So far we have made some progress in understanding what they are, but we don't know exactly what they are. The techniques of recombinant DNA and genetic analysis are available and can be applied. They are expensive, they take a lot of time, but they are available.

Fourth, studies of nerve growth factor: In animals, we now know there are a number of chemicals that are produced in the normal brain that are required for the normal development and maintenance of nerve cells in the brain. These chemicals have been discovered only in the past few years and it is entirely possible that the major cause of Alzheimer's disease, the most immediate cause, is a defect in one of these chemicals which then has a secondary effect that it causes normal cells not to develop or to die prematurely.

There is no direct evidence that those chemicals are involved in Alzheimer's disease, but we know how to measure some of them, we know how to begin to look at what their role might be in Alzheimer's disease.

The final area I think is going to be very important, the development of new potential diagnostic techniques such as positron emission tomography. Positron emission tomography is a method by which we can actually look at chemicals in the brain of a living person by injecting a target chemical that has been labeled with a positive emitter that can be measured when that person is put into an imaging machine. It is like a CAT scanner, but rather than looking at the brain structure it looks at brain chemistry. We know Alzheimer's disease has associated with it certain chemical abnormalities, and certain techniques such as this will ultimately enable us to look during life at the abnormalities that we now see only after the person has died. Once again, these are expensive types of studies and we don't know that they are going to work.

In summary, I would like to say that I think from a scientific point of view there are lots of important avenues to pursue. Unfortunately, as people in the panel earlier today testified, they have not as yet had a dramatic impact on the lives and ordinary care of patients who are presently getting this disease. However, I think it is very clear that unless we begin to do these kinds of studies, we are not going to make a major change in the way this disease is currently treated. Hopefully, with additional resources such as have been brought to bear in the Alzheimer's disease research centers, a lot of these important areas will be developed further and one or more of them will lead to important changes in the way Alzheimer's disease patients are diagnosed, treated and ultimately, I hope, the disease could, in the future, be prevented.

Thank you very much.

[The prepared statement of Dr. Mohs follows:]

PREPARED STATEMENT OF RICHARD C. MOHS, PHD.

Congressman Mazarek and Members of the Committee: Thank you for the opportunity to speak before you here today. I would like to talk to you about the research that we have been conducting on possible causes, diagnostic tests and drug treatments for Alzheimer's disease, a health problem that has become well known to this committee. I am speaking today as a representative of one of the ten Alzheimer's Disease Research Centers (ADRCs) funded by the National Institute on Aging. Our center is located at the Mount Sinai School of Medicine and the Bronx VA Medical Center. The Center is directed by Kenneth L. Davis, M.D., who is also professor of Psychiatry and Pharmacology at Mount Sinai and Chief of Psychiatry at the Bronx VA Medical Center. Dr. Davis is also a resident of Huntington, Long Island and, although he is unable to attend this meeting today, would be pleased to assist Congressman Mazarek and the Committee if needed in the future.

The Mount Sinai/Bronx VAMC ADRC has associated with it over 20 medical scientists and numerous technicians who are engaged in research on all aspects of AD. These include studies of new diagnostic techniques, studies of potential treatments, studies of the disease course and it's impact on families, studies of possible animal models and, last but not least, studies of possible causes for AD. I will describe briefly some of the studies currently being conducted at our Center and at other Centers around the United States. From the point of view of someone who has been involved in research on AD for over 10 years it is very clear that tremendous progress has been made in several important areas: the neuropathology and neurochemistry of AD are known in much more detail than previously; methodology for good clinical trials of potential therapies is reasonably well established; diagnostic practices around the country have improved; and, possibly most importantly, even though the causes of AD are still unknown, the major possible candidates for a cause have been described and methods for their investigation are available. Taking the next steps in AD research will be difficult, costly, and will require fairly large, multidisciplinary teams of investigators who have contact with both basic science laboratories and with clinical centers where patients with AD are treated. The 10 currently established ADRCs provide a good base for continuing the work that has led to our current optimism about AD. However, we must face the fact that these centers are currently underfunded, that they face additional funding cuts in the next two years and that many

potentially valuable new projects at these Centers are not being done because they lack the necessary dollars.

Several lines of research could lead to major advances in our understanding of AD, and in our ability to treat and possibly prevent it. They include:

1. Studies of brain grafting. Work at our center and other centers clearly shows that brain cells can be viable if transplanted into animals with nerve cell loss. They can also restore some functional capabilities in these animals. Numerous studies must be done to determine whether analogous procedures might benefit AD patients.
2. Genetic and other causes. It has long been known that some cases of AD are transmitted genetically. Our own work and that of others now suggests that a genetic factor may be involved in most cases of AD but the mode of inheritance is obscured by the very late age of disease onset. Also the interaction of possible genetic and other potential risk factors such as infections, head injury etc. can only be investigated with lengthy studies of large populations.
3. Cystoskeletal abnormalities. The abnormal proteins in brain cells of patients with AD have now been described in some detail. However, further understanding of where these abnormal proteins came from will require studies with expensive recombinant genetic techniques.
4. Nerve Growth Factor. Several important chemicals that are necessary for normal growth and maintenance of brain cells have been discovered. Loss of these chemicals may play a role in AD. Studies must also be conducted to determine whether drugs designed to stimulate or replace these chemicals might be used to treat patients with AD.
5. Positron Emission Tomography (PET). The technology for measuring chemical activity in the brain of a living human is now available. Essentially it involves introducing into a patient's bloodstream chemicals labeled with positrons which can then be detected as they are released. Since several neurochemical abnormalities in AD have been described, PET studies may lead to a much more specific diagnostic test than is possible with other imaging techniques such as CT scan which gives only structural information.

Over the past 10 years our research group at the Bronx VAMC and the Mount Sinai School of Medicine has conducted numerous studies dealing with AD. These efforts have expanded since 1985 when we were awarded one of the first 5 ADRCs from the National Institute on Aging. We are now pursuing studies in several of the areas described previously. I will now give a brief summary of some of our work from the past 10 years.

A series of studies conducted in the United Kingdom in 1976 and 1977 reached an extraordinary conclusion about Alzheimer's disease. Three laboratories working independently reported that in AD, there was a loss of brain cells that made the neurotransmitter acetylcholine. This conclusion was based upon the discovery that the enzyme which synthesize acetylcholine, and is only found in brain cells that make acetylcholine, (i.e. cholinergic neurons) was very much reduced in the brains of patients with AD.

This finding led a number of research groups, including our own at the Mt. Sinai School of Medicine and the Bronx VA, to suggest that a possible treatment for AD would be a drug that could increase brain cholinergic activity. Such an attempt was particularly appropriate to our research group, because we had been investigating a drug that increases brain acetylcholine, physostigmine. Physostigmine inhibits the breakdown of acetylcholine. In fact, while neurochemists in the United Kingdom were finding that the brains of patients with AD had a cholinergic deficit, our laboratory was conducting a study of the effects of physostigmine in memory in young normal people. We found that the administration of physostigmine to young normal people could improve their ability to remember new information. The simultaneous discovery of the acetylcholine deficiency in patients with AD, and the ability of drugs that increased brain acetylcholine to enhance memory, led to the idea that the memory disorder in AD might be improved with drugs like physostigmine.

The earliest trials of cholinomimetic therapy for AD usually involved either choline or phosphatidylcholine (lecithin), precursors to acetylcholine that are safe even in large quantities and which are normally obtained in the diet. It has been demonstrated in rats that increases in dietary choline or phosphatidylcholine are followed by increases in the concentration of brain acetylcholine. Clinical trials, however, failed to demonstrate any acute effect of these precursors on memory or other aspects of cognition, either in unaffected people or in patients with AD. The reason for this failure appears to be that precursors do not substantially affect the rate of cholinergic transmission even though they may increase acetylcholine concentrations.

With the help of a program project grant from the National Institute on Aging, as well as support from the Veterans Administration, my colleague Kenneth L. Davis and I began a study of physostigmine in AD. We first administered an intravenous form of the drug and then an oral preparation. The initial studies with intravenous physostigmine were encouraging, although the ability of physostigmine to improve memory was hardly as robust as one might have hoped. Still, additional studies were necessary, because intravenous physostigmine is so short acting that it

was impossible to adequately assess whether the drug would help patients in daily life.

Of the first 11 patients who completed the study of oral physostigmine 10 showed some decrease in symptoms with at least one of the physostigmine doses. Of those, 8 again showed less severe symptoms while receiving physostigmine in a replication study than they did while receiving placebo. From a clinical perspective, only 3 of the patients demonstrated enough improvement to be clinically relevant. However, there is very good reason to believe that not all patients with AD will respond to this drug, nor will all patients who respond to physostigmine respond in the same way. This problem arises from the fact that for physostigmine, which prevents the breakdown of existing acetylcholine, to work, the brain must be able to synthesize some acetylcholine. Unfortunately, as the disease progresses cells which ,ynthesize acetylcholine are dying. Because of this problem we needed some way, besides memory testing, to be sure the physostigmine was getting into the patient's brains. In collaboration with an endocrinologist in our laboratory, Dr. Bonnie Davis, we have found that when physostigmine enters the brain, and acetylcholine containing cells are available to synthesize adequate quantities of acetylcholine, the physostigmine increases the amount of cortisol the patient's body secretes at night. The effect of physostigmine to increase nocturnal cortisol concentrations correlates with the drug's ability to improve the symptoms of AD, as the figure below indicates. These results support the notion that physostigmine only improves the cognitive functioning in those patients whose acetylcholine containing neurons have not yet been devastated by the disease.

Although these results are encouraging to the scientist, for the patient with AD the effects are not as impressive or uniform as one would desire. Instead, they only point to other directions that must be pursued and better drugs that must be developed. Nontheless, these results with oral physostigmine, which have been replicated in at least 5 other laboratories, indicate that current approaches are rational.

Whatever the results of the studies in progress, it is clear that not all patients are going to be helped by physostigmine treatment, and that those patients who are helped will not be returned to a normal life. For that reason, additional work is necessary. To that end, our program has been engaged in developing an "animal model" of Alzheimer's disease that may expedite development of other drugs. These studies are made possible by a merit review grant from the VA to me and my colleague, Dr. V. Haroutunian, as well as collaboration with the Hoechst

Roussel Pharmaceutical Corporation. Together, we have found that destruction of a tiny part of the rat's brain can produce a deficit in acetylcholine that in many ways resembles the deficit that exists in AD. This rat model makes possible the screening of drugs for their ability to improve the memory of "demented" animals. We are particularly encouraged by one compound that increases both Ach and NE, another neurotransmitter deficient in some, but not all AD patients. This, and other promising compounds are now being tested in toxicological studies preparatory to human investigations.

In the future, and with the help of the NIA's ADRC new drugs that might be more efficacious will be tested, and more importantly, the model will be extended so that it even more closely resembles the human condition. Other neurotransmitter and neuromodulator deficits, particularly of noradrenergic neurons and somatostatin concentrations, will be induced. In addition, with the help of funding from the VA and the NIA, we are now transplanting brain tissues to these lesioned animals in the hope of normalizing their behavior. This will be a difficult process, but one with obvious implications for developing a treatment for Alzheimer's disease.

This concludes my statement, I would be pleased to answer any questions that you or members of the Committee may have.

STATEMENT OF DR. PAUL HELMS

Dr. HELMS. I would like to thank the committee for the opportunity to present at this hearing along with Dr. Henn at the State University of New York at Stony Brook.

In the 4 years that I have been at Stony Brook, in addition to attempts to increase the research in the area of geriatrics, and particularly Alzheimer's disease, we have attempted to improve and increase the clinical services available at that institution. Particularly, we have developed an outpatient geriatric division, and over the last year alone have evaluated 134 patients, 86 of which we follow actively. The majority of these patients, have dementia of the Alzheimer's type.

We have been studying drug treatments, we have also been very interested in studying the effects the illness has on family members. We have applied for funding specifically in order to study the effect, both psychologically and physically, on family members caring for Alzheimer's, relatives in the community, the primary focus of care for the patients, as indicated by the first panel.

Our clinical and research experience, I think, has provided us with some understanding into the problems faced by the elderly, as well as the families of the elderly Alzheimer's patients. Clearly, as indicated by the other panelists, the No. 1 research issue to be addressed is inadequate treatment for dementia of the Alzheimer's type. This, of course, as indicated, is intimately related to an understanding of the etiology of this disorder. However, until this treatment is found, it is important to emphasize, both in research and clinical areas, the management of the individual with dementia. This has to include methods of providing aid for the family. And in this area there is a specific need.

Medicare, unfortunately, has seen fit to decrease the amount of coverage for psychiatric care. This has affected our ability to work with older patients and their families with Alzheimer's disease. The funding has been cut back.

We need to further study the techniques to manage the complications. As a clinician primarily, I have often referred individuals that have questions of managing behavioral disturbances that have come up. This is an area we still unfortunately know extremely little about. We do know, however, that the available drugs in 1986 have not proven to be terribly effective. We also need, obviously, to educate physicians as well as family members. Clearly, the Alzheimer's disease and related disorders socially has been invaluable in aiding, educating family members. However, and unfortunately, they reach only a portion of family members caring for Alzheimer's victims. They also, obviously, do not reach many of the physicians who are the regular physicians of such individuals.

Public education programs continue to be necessary in this area. There certainly has been movement, but further movement is necessary as well. There is an extremely important need to better educate physicians in this particular disease. Beyond psychiatrists, geriatricians, and neurologists, the general family physician needs to be better educated. This needs to start in medical school and progress through residency and, obviously, requires funding.

Although I do not believe that we can transpose a system from England to the United States, I think respite care in England has taught us some lessons. Although respite care is still in its infancy in the United States, it certainly has proven to be beneficial, in my clinical experience, for some families that I have worked with.

It is important to develop additional programs and along with this, additional day treatment programs, and much of this was alluded to in the first panel.

One of the limitations alluded to was the matter of transportation; and further work in this area, particularly because of the nature of Suffolk County, needs additional work.

The expectation is that programs such as respite and day treatment will decrease the adverse impact of caring for demented relatives and potentially enable these individuals to be maintained in the community for longer periods of time with less impairment to the relatives. There is little doubt of the adverse effects of poor institutional care and the potential benefit of excellent care within the family matrix. However, we are still unable in many cases to draw firm conclusions because of the lack of research in choosing between these operations in a large number of cases. It is important that respite care day treatment and home health aides be accessible and this means both physically and financially, as well as qualified.

On numerous occasions, we have seen excellent home health aides leave for other positions due primarily to salary rates. We have also noted considerable variability among aides both in their motivation and ability to care for the elderly. No matter how successful home care is, a percentage of elderly, particularly those with dementia of the Alzheimer's type, will require institutional care. While there is anecdotal cases of significant improvement in certain nursing facilities, there is yet to be compelling evidence of widespread changes, particularly in dealing adequately with the Alzheimer's patient. Programs to maintain the quality of life need to be developed further in institutions as well as in the community. But they need to be assessed as to the value of these programs, so that we can, in the future, rationally choose between a wide variety of possibilities.

It is not uncommon to meet with difficulties in attempting to find nursing home placement, as already noted. Alzheimer's disease patients, particularly, run into difficulty because of the Medicaid difficulties cited. Obviously, it is not possible for one group or agency to adequately tackle the problems faced by these individuals, particularly the frail and demented elderly. It will be necessary for local, State and Federal agencies, along with the private sector and the medical community, to work together to address these issues.

[The prepared statement of Dr. Helms follows:]

PREPARED STATEMENT OF DR. PAUL M. HELMS

I came to the State University of New York at Stony Brook and University Hospital in July of 1982. Since that time I, along with my colleagues, have worked to increase and improve the clinical services for the elderly and the research in geriatrics. As a result the number of elderly treated on our acute care inpatient psychiatric service has been increasing. We have also developed an active outpatient geriatrics psychiatry division, particularly with the addition of Dr. Murty Ayyala and Dr. Lory Bright-Long, currently a fellow in geriatric psychiatry. In the last year we have evaluated 134 geriatric outpatients and are actively following 86 of them. The largest portion of these patients are individuals with dementia, particularly dementia of the Alzheimer's type, and depression. Research has focused on dementia of the Alzheimer's type and depression. We have been studying drug treatment of dementia, effects of antidepressant medication on cognitive (intellectual) function of elderly depressives and are applying for a grant to study the effects of different interventions on the physical and mental health of relative caregivers of patients with dementia of the Alzheimer's type. This clinical and research experience has provided us with a better understanding of the problems faced by the elderly as well as their families.

Clearly the number one research issue that needs to be addressed is the search for an adequate treatment for dementia of the Alzheimer's type. This, of course, is intimately related to research into the etiology of the disorder. Until a treatment is found; it is important to continue to emphasize, both in research and clinical care, the management of individuals with dementia. This has to include methods of providing aid for the families. There needs to be further studies on techniques of managing the complications of dementia as well as ways of training and educating physicians in these methods. The Alzheimer's Disease and Related Disorders Association has certainly been an invaluable asset for disseminating available information to participating relatives. They, however, only get to a portion of family members. Other public education programs are needed as are programs to educate the physicians managing such patients. This includes not merely psychiatrists, neurologists and geriatricians, but general internists and family physicians as well. Although I do not believe that we can transpose systems used in England to the United States, I think there is a lesson to be learned in the area of respite care. Respite care has made care of the demented and physically impaired elderly in the home more feasible. Respite care, however, in the United States is still in its infancy. It is important to develop additional respite programs to assist the family members wishing to care for their impaired relatives. It will be also important to assess, through research, the effects of this intervention on the family members. On a more regular basis, day care would appear to be an important adjunct to home care of cognitively and physically impaired relatives. One of the limitations of the day treatment has been transportation to and from the day treatment programs. The expectation is that programs such as respite and day treatment will decrease the adverse impact of caring for a demented relative and potentially enable these individuals to be maintained in the community for a longer period of time with less impairment in the relatives. There is little doubt of the adverse effect of poor institutional care and a potential benefit of excellent care within the family matrix, however, we still have very little research to guide us in choosing between home care and institutional care in many cases. It is important that respite care, day treatment and home health aids be both accessible (physically and financially) as well as qualified. On numerous occasions we have seen excellent home health aids leave for other positions due primarily to the salary rate. We have also noticed considerable variability among aids both in their motivation and their ability to care for the elderly. No matter how successful home care is a percentage of elderly, particularly those with dementia of the Alzheimer's type, will require institutional care. While there is anecdotal cases of significant improvement in certain nursing facilities there is yet to be compelling evidence of widespread changes. Programs to maintain the quality of life need to be developed further in institutions as well as in the community. It is not uncommon to meet with difficulty when attempting to find nursing home placement for an individual with dementia of the Alzheimer type, particularly where the individual with Medicare/Medicaid.

It is not possible for one group or agency to adequately tackle the problems facing the elderly, particularly the frail and demented elderly. It will be necessary for the local, state and federal agencies, the private sector and the medical community to work together to address these issues.

Mr. MANTON. Thank you, Dr. Helms.

Our last panelist, Dr. Ronald M. Lazar, and then we will get into some questions.

Dr. Lazar?

STATEMENT OF DR. RONALD M. LAZAR

Dr. LAZAR. Thank you.

I want to thank the Congressman and committee for the opportunity to address you today on some of the clinical aspects of Alzheimer's disease from the viewpoint of a nuerologist. We are the ones out in the field who have to see these patients in our offices and clinics and we are confronted with the issues of whether or not the person has a disease that requires treatment. I wish to note at the onset that my experience with this illness extends beyond the hundreds of dementia patients seen at Downstate Medical Center and Community Hospital at Glen Cove; Alzheimer's disease was the likely cause of my own grandmother's death 2 years ago.

It is becoming increasingly apparent that dementia of the Alzheimer's type represents the most common cause of intellectual deterioration in older persons, according to both clinical and neuropathologic investigations. The diagnostic dilemma for the clinician, however, is twofold: First, there are more than 60 identifiable causes of dementia besides Alzheimer's disease, such as stroke, tumor, trauma, infection, toxic and metabolic disturbances, and vitamin deficiency. It is not uncommon for multiple causes of dementia to exist in the same patient.

Second, definitive diagnosis of Alzheimer's disease at this time can only be made by examination of brain tissue. We are, therefore, left with the clinical presentation of our patients, especially in the early stages of the disease when there are normal laboratory studies, and nonspecific findings on the electroencephalogram and neuroradiologic studies. It is the neuropsychologist who is often called at this point to quantify the nature of the disorder.

The Diagnostic and Statistical Manual of the American Psychiatric Association regards dementia as a progressive decline of cognitive and intellectual abilities sufficient to interfere with social or occupational performance. The areas of function include memory, language, cognition, visual-spatial abilities, personality, and motor skills. The role of the neuropsychologist, as a member of the interdisciplinary health-care team, is to administer appropriate psychometric tests to document empirically the degree of deficit in each one of these functional areas and to monitor change over time. Let me outline briefly the nature of the deficits identified by neuropsychologic evaluation that have correlated highly with autopsy findings consistent with Alzheimer's disease.

Memory loss is frequently the initial presenting disorder. Memory is not a single process but a group of interrelated mechanisms, some of which are more affected than others in the early stages of disease. Patients with presumed Alzheimer's disease have difficulty forming new memory, as judged by their disorientation for time and place, and failure to retain new information shortly after it is presented to them. The recall of old information is often less disrupted until later stages of the disease.

Language disorders represent a second feature of dementia of the Alzheimer's type. Conversational language has an empty quality, which is notable for the lack of substantive words and the presence of pronouns without antecedents. The ability to repeat words and sentences may be intact, but naming and language comprehension progressively deteriorate. Syllable substitutions and reversals in the verbal output become more frequent, until strings of syllables are put together with no meaning at all. Such language deficiencies, known collectively as a transcortical aphasia, are not commonly found in many other kinds of dementia. It is not true that patients do not understand because they are confused; rather, they become confused when they fail to understand the communications of others.

Cognitive deterioration is another early sign of dementia of the Alzheimer's type. Patients often display poor performance on measures of calculation, reasoning, interpretation of proverbs, and problem solving.

Visual-spatial skills are often severely affected, and in some atypical cases may be the first behavioral manifestations of this illness. Patients lose their way even when traveling across familiar routes. They have difficulty dressing as well as copying even simple geometric figures. The ability to use their hands to construct things becomes seriously diminished.

The patient's personality and emotional function also undergo change as intelligence deteriorates. Although depression can be an early symptom, it is not common in Alzheimer's disease. In contrast, patients become progressively indifferent, with little indication of the ability to plan for the future. We do see emotional swings, and it is not uncommon to find irritability and even paranoia.

The last area of evaluation concerns motor function, which appears to be a later rather than earlier finding in the neuropsychological evaluation. Other dementias, such as those caused by Parkinson's disease, Huntington's disease, progressive supranuclear palsy, and Lou Gehrig's disease are often associated with disorders of movement, gait, and posture. We measure psychomotor speed and assess characteristics of speech to provide an index of motor skills.

With these six functional areas in mind and the neuropsychologic measurement tools at our disposal, we are asked by the neurologist or the psychiatrist to answer the following questions:

First, is there an acquired impairment of intellectual function?

Second, if a disorder exists, does it resemble Alzheimer's disease, or some other pathologic process?

Third, is a change in intellectual function caused by dementia or by depression?

The picture provided by our data is then integrated with the findings of other medical professionals and a diagnosis is made. When there is little information regarding preillness levels of function, the initial neuropsychologic examination often must serve as a basis of comparison against which subsequent deterioration can be judged. It should also be noted that neuropsychologic testing identifies areas of strength in patients with dementia that we use

in the treatment and rehabilitation process—even if such help is temporary.

Let me say, in conclusion, from the viewpoint of the clinician, we are in desperate need of information to be able to provide these kinds of diagnostic services by various research efforts outlined by Dr. Makman, Dr. Henn, Dr. Mohs, and the kind of clinical services available at Stony Brook that my colleague here has also identified. We must know more about how to make the differential diagnosis, Alzheimer's versus other kinds of dementing processes, some of which are reversable. We must build a greater armada of both invasive and noninvasive diagnostic procedures. We need more research in understanding the neurochemical markers that might provide a good correlation with our behavioral data to get an earlier diagnosis. There must be improved documentation of the nature of the clinical deterioration, as Dr. Mohs' group has been interested in for years, but more data is clearly needed.

Finally, the patients come to my office and we make a presumptive diagnosis based on all the evidence available, but what do we do with our patients? The financial resources that have been outlined by Ms. Kennedy and others indicate that often patients are told they have a disease but where to go next is often the most difficult question to answer. I would urge the committee and the Congress to look at areas such as home health care, increased funding for Medicaid, toward the notion of increased funding for Medicare for the catastrophic illness so that these people who we have to see in our offices can take advantage of the kinds of procedures being developed in the research field. Thank you.

Mr. MANTON. Thank you, Dr. Lazar.

Mr. Mrazek has a question, I believe, for Dr. Henn, who has to leave. Then, perhaps, we can get on with the other panelists.

Mr. MRAZEK. I don't necessarily know that this is a question just for Dr. Henn—actually, it is a question for anyone who would, probably, want to make a contribution as far as the answer goes.

Under the National Institute on Aging, we do have the 10 centers established for research. I would like to ask how effectively do you think that that program is working, particularly for those doctors who are participating at one or more of the centers? And even those doctors who aren't participating at a particular center that is now being funded, I am curious to hear your impression of what the Federal role should be, from a research standpoint, whether the resources in terms of funding levels is so low at this point as to be really inconsequential as far as finding answers in the near-term future to some of the research challenges you are undergoing.

Dr. HENN. Let me comment.

Stony Brook is not one of the centers, but I happen to know something about them because I am on the advisory panel to the National Institute of Mental Health that site visits and determines who is going to get the money. So I visited several, and I know what is going on, for instance, at Mount Sinai.

I think the program was to be viewed as a success and I think the 10 centers are making a significant and major contribution to research in the area. I think it is imperative that they be continued because I think the outline you heard from all of us is that the areas of research are complex. Probably any one of us could take

any one of the issues we have said and tell you a story that would get you very excited about the possibilities of cure. Another one of us could tell you the reasons why it might not work. So we have to go forward on all the fronts because we just don't know where the answers lie.

My evaluation is that the center mechanism is important, ought to be continued. Ideally, since we are developing a new program at Stony Brook, this may be a little self-interested, I would like to see a few more centers added because we are going to be in a position to apply for one.

I think a lot of the studies are longitudinal and the worst thing that could happen now would be a break in funding. The value of the information is going to be collected over time so it would really be very cost infective if this program were cut.

Dr. MOHS. Well, as a person who does work in one of the centers, I may sound a little self-interested for myself as well, but we worked very hard to get our center, and the centers were only given to places that had already established themselves as having active research programs.

I have been to several meetings of the center directors and I will say that the establishment of these centers has brought together groups of people from the basic sciences, clinicians who otherwise would never, ever have been brought together to begin to develop strategies for researching Alzheimer's disease.

There are a couple of points I think worth making: One, I would like to re-emphasize what Dr. Henn said. It would be a terrible thing to have any break in continuity. Basically, every one of the centers has, as part of its mandate, to establish a longitudinal study of patients with Alzheimer's disease who are then taken to autopsy so we can get tissues. It is unfortunate from a certain point of view that the only organ of the body which we know to be directly affected by this disease is the brain. If you want to study the disease, you have to have access to that brain tissue. So every center has established a mechanism for following patients to autopsy in an effort to obtain that brain material.

Second, I don't know whether or not the Congressmen know this, but there is a chance that in the next year that the Alzheimer's disease centers will be cut, in fact, 20 percent. They are slated for a 20 percent cut in funding already next year, even though they have only been in operation 1 year, which is obviously going to damage some of the efforts we have already made to get going and get our patient groups established and our laboratories functioning and so forth.

The third point I would like to make is that although we have brought to bear on the question of Alzheimer's disease a lot of people who otherwise would not have been doing work in this area, the fact is that the funding levels we are talking about are really rather small in comparison to either of the two standards we might want to use. One is in comparison to the money spent on other major diseases in the United States, for example cancer, where the funding for the National Cancer Institute is probably 50 times what we spend on Alzheimer's disease.

Mr. MANTON. Why don't I interrupt.

Just for the record, I was sitting here as you were talking, making a little computation. I hope it is correct. My memorandum shows that we are spending about $446 million a year on Alzheimer's and related disorders, and 2.5 million people are suffering from Alzheimer's disease. That comes out to a monumental total, I think, of $17 per person, which is a disgrace.

Sorry to interrupt, but I would like that to be in the record.

Dr. MOHS. I think those numbers tell a good part of the story. I think one other way to look at this is to consider the amount of money that it costs to care for people who have the disease in comparison to the amount of money we are spending trying to keep these people from having the disease or the amount of money we are spending trying to keep them out of institutions and at home where it would not cost us $4,000 a month, or whatever the figure was. And that hardly tells the story in comparison to the loss of happiness and loss of productivity of the lives of five family members involved in taking care of this one person.

We have made some steps forward. What I want to impart to you in my testimony is I don't believe you can solve a problem just by putting money in it. But there are things money can do, and they are reasonable things to do. Money can make a difference.

In this case area there are reasonable things to do. There are plenty of people out there now willing to put in the effort to work on the problem, if the money is available. In that sense, the amount of money currently available for research is far less than could be used productively.

Dr. MAKMAN. I just want to say, of course, I agree fully with what has been already said, that in fact the number of centers should be extended. Also, I think currently studies and help in Alzheimer's is coming, not only from the National Institute on Aging, but also NIMH. These institutes each have something important to contribute. A variety of programs and researchers investigating is really our best resource to both the basic and clinical aids that we can make and contributions we can make.

It is hard to know at this point where the most important contributions are going to come from, but we really have the setting for making the contributions. The amount of money that is being spent is ridiculously low, I think, in terms of the medical benefits we can get from increasing the spending on the clinical level and long-term benefits we can get from increasing the basic research.

Mr. MANTON. It was wrong. It is $170, which I still think is a disgrace. I want to correct the record.

We had a question submitted about aluminum as a possible toxic agent. In fact, the question mentioned an aluminum foundry. Does anybody want to take a crack at it?

Dr. HENN. There is a model for aluminum. If you put aluminum in the brains of rabbits or rats, you can create a lesion that pathologically looks very similar to Alzheimer's tangular plaque. The problem is there has been no post-mortem evidence that aluminum toxicity plays a role in the tangles, as far as I know.

Dr. MOHS. That's correct. We happen to be in the fortunate position of just having a new head of neuropathology at Mount Sinai who is one of the people who found that aluminum is associated with the dying cells in the brains of Alzheimer's patients. That was

one of the pieces of evidence, along with the rabbit model, that suggested that aluminum might be a pathologic agent. However, there is no good population data to suggest that people who are exposed to more aluminum are any more likely to develop the disease.

Also, on the microscope, there are differences between the pathology of the rabbit model and true Alzheimer's disease. So, I think even Dr. Pearl, if I could speak for him, would agree that aluminum plays a role in the development of Alzheimer's disease, it is a contributory factor. In other words, it is not a lone cause, but it may react in some people with other things, like a genetic predisposition or a virus, to speed the disease along or hasten the onset. But it is certainly not regarded as a single causative factor at this time.

Mr. MANTON. Talking about genetic predisposition, some diseases seem to have a higher incidence in certain groups. Is there any ethnic group or other group that is more predisposed genetically? Is there any scientific——

Dr. MOHS. This is one of the areas where we don't have nearly the kind of data that we would like. The National Institute on Aging has been working with the World Health Organization, which is a political as well as a scientific process—you may know that—to try to put together some cross-national studies to see whether the rate of disease varies substantially from one ethnic background to another. As near as we know, the disease is common in all Scandinavian countries, Western European countries, the United States, and Japan. Whether or not it is common in developing countries, we don't know because most people in those countries don't live long enough to develop the disease. There is an effort underway now to ascertain whether or not it is prevalent in China.

The only direct evidence on the question that you have raised is a study that was done in Israel and reported a couple of years ago, demonstrating that people in Israel whose background is European tend to have a higher rate of Alzheimer's disease than people living in Israel whose background is primarily Middle Eastern. So that there may in fact be some population groups who are slightly more predisposed to develop the disease. Really, it is one of the questions we have the tools to begin to look at, but we don't know the answers very well.

Mr. MANTON. One of the other questions submitted related to progress in this area in Europe. Are there any advances there that we should know about?

Dr. HENN. I think the brain grafting, which Dick told you something about, is going on with some vigor in Sweden, and they are among the leaders right now in that field, as is a group at Cambridge, England, although groups at our school and your school and spread throughout are also doing brain grafting successfully. In addition, there are head-scan studies now coming out of Sweden, and I think epidemiology in Scandanavia has also made a major contribution.

The problem with developing countries, if I can add a footnote to the last question, is that a lot of times they just haven't asked the right questions—for instance, China. We had roughly had someone go over to China and they were told there was no Alzheimer's dis-

ease. But when they went out in the field, they also became clear they weren't asking, weren't even looking for it. It is hard to know how to evaluate data.

Mr. MANTON. Mr. Mrazek?

Mr. MRAZEK. I think the Soviet Union indicated they don't have any Alzheimer's disease.

Dr. HENN. That's right. They didn't have radiation problems either.

Mr. MRAZEK. A number of questions submitted by the audience, I would suggest, have been answered, or at least have been touched on by the panelists, and it is pretty clear that there are no specific answers to some of those questions. If your particular question hasn't been asked or isn't asked between now and the end of the hearing, perhaps you might want to try to address it specifically to one of the panelists before they leave.

One of the questions which I thought was worthwhile for families who are dealing with this situation on a personal level was what would be the pros and cons, what would be your recommendations for families to participate in clinical research where their loved one might be involved in research with new medications and so on.

Dr. HELMS. I can, I think, address that.

I think that obviously has to be addressed on a specific individual basis. Having done work in that area, certainly there are many family members who are very, very interested in pursuing that. I think so long as the research is appropriately qualified so as not to give any false hope or so as to assure, as much as possible, not to give false hope, many family members, in my experience, feel that is another thing they have done to do everything that is at all possible.

I have also found with many family members, that there is a very strong interest for the greater good, beyond what might happen in their individual family member's case, and I think that is an important part and that is one of the things we address when we request a consent.

Mr. MRAZEK. Another question from the audience involved the fact that in various news media reports there are often new so-called promising drugs outlined in these reports for Alzheimer's patients. For instance, a drug called Vinpasetmin or Vinposatine (phonetic). How can families find out what institutions are involved with research dealing with specific types of drugs and whether it is something they ought to be pursuing to see whether their loved one could be treated with that drug.

Dr. HELMS. You did a better job pronouncing the name than I did. That is actually the last one I came across as well. It is a question I am asked very frequently. I think it is one of the areas of Alzheimer's disease and related disorders that has been a tremendous help as one of the services that serves as a clearing house for information and directing families. To my knowledge, there is no other centralized system of ascertaining who is doing what in this area. We certainly do know what is happening in New York City at Mount Sinai or NYU or Albert Einstein, and have referred family members to those institutions.

One of the things I spent a lot of time doing as a clinician is trying to explain why the New York Times, as fine a newspaper as it might be, sometimes makes things sound better than they in fact are, or worse than things are, I guess, in some cases. I think that is important. I think that through the ADRDA, I think a lot of families have come to better understand the limitations of the public press in terms of disseminating that information.

Dr. LAZAR. The public also has to be educated to the fact that these are clinical investigations that are being carried on, and there are fairly rigorous eligibility criteria for patients to be involved in these particular studies; that it is not for everyone. That they are just beginning to ask the important questions about those kinds of drugs and establish the most reliable data base. They have to deal with very restricted populations in the beginning and as efficacy is established, expand it to a broader base and ultimately to clinical use.

When there are reports in the New York Times about substances being quietly used throughout, and that it is going to be the next cure for brain disease, it leads to a lot of false hopes that it is going to be a cure for the relative when that in fact does not exist.

Mr. MRAZEK. Would it be fair to say for families interested in pursuing perhaps a clinical research commitment with a loved one that the social agency is the best clearing house for that kind of information?

Dr. LAZAR. I think that would be an appropriate mechanism, yes.

Mr. MRAZEK. That being the Alzheimer's Disease and Related Disorders Association?

Dr. LAZAR. Correct.

Mr. MRAZEK. I am confident that you, Dr. Mohs, representing a center that is presently being funded, would recommend that if there is no increase in funding that there will not be an increase in the number of centers receiving funding—because I assume that would mean a reduction in funding, with the limited mathematical capabilities that I have, for the centers presently receiving funding.

Dr. MOHS. That is certainly a fair statement. When the centers were created, it was deemed that anyplace that had a research program of such size to be called a center would have to have certain components. One would be an autopsy core; one would be a group of people who would be expert on recruitment of patients and diagnostic evaluation; one would be a group to follow people longitudinally; and the other would be an administrative and public information group. And I forgot, something to manage your data; you have to have some computers. If you put those together, that takes a lot of money just to do that.

The funding level of the centers at present is just slightly above what you need to have the very basic things that were thought to be absolutely necessary for the centers. So the centers are really not terribly well funded in terms of their resources right at the present time. If the centers were expanded without distributable funding, essentially what you would have is no longer centers; what you would have is more like smaller grants rather than true research centers.

Dr. HENN. If I might, I might actually agree with that, you will be surprised to hear. Coming from a fairly new medical school and

the life of a medical school only a decade old, Stony Brook obviously isn't grown up yet. We weren't quite ready to apply for a center, but I would still agree you shouldn't cut the current centers any more. We are now in a position where Sinai was 3 years ago, and we have some other interesting avenues of research we think are unique and opening up. But I think for us at this point, we can pursue them through other mechanisms, rather than cut the existing centers because I think you will lose the longitudinal data.

Mr. MRAZEK. Do you think there should be any consolidation as far as the agencies involved, in providing financial resources on a Federal level? Should, in other words, there be funding provided by NIMH as well as the National Institute on Aging and any other agencies?

Dr. HENN. I think there should be, for the following reasons: The kinds of research that I alluded to earlier, that was evaluative research in terms of how you care for people best who already have the illness, and what things make a difference, that is appropriate for NIMH. I think that the National Institute of Aging should handle a specific aging related basic work that Dick has talked to you about, but I think NINCDS, the neurology and stroke group, which does the basic neuroscience in this country, should also be involved in funding projects that might apply to Alzheimer's. The problems of normal aging and problems of how the brain adapts and has plasticity, how it can change. So I think it is appropriate to have different centers.

Mr. MRAZEK. Do you have any comments to make about the peer review process for applying for grants at this point and whether it in fact is the fairest way to see tha funds are distributed to groups of either clinicians or research physicians who are seeking the resources necessary to pursue this?

Dr. HENN. As somebody who is on both sides of the process, on the panel that gives out money and, obviously, trying to get money, I think there are lots of problems with it, but I still think it is the best we can do.

Dr. MAKMAN. I also would agree with that, to support the current system, as it is the best we have. Also, I think, an important aspect of the system to have it work is, in fact, to have funding from a number of institutes reviewed by a number of different study sections. That fits with NIMH and NINCDS and the Aging Institute, supporting this research.

Dr. MOHS. I can second those remarks. There are any one of us who has applied for grants who can tell you of times we thought the decision for the peer review process was the wrong one. However, I think there is no other system in the long run that will be as fruitful in getting the money to the people who can make the best use of it.

Mr. MRAZEK. As a member of the House Appropriations Committee, I can tell you some of my colleagues think they are qualified to determine that. I guess your response is that perhaps the peer review process is superior to the Appropriations Committee's determination.

Mr. MANTON. Getting back to something mentioned as perhaps one of the causes, some mention was made of chemicals and/or vitamin deficiencies. If I recall correctly, another mention was made

that talking about Alzheimer's disease is relatively new, going back to the early 1980's.

Is Alzheimer's something that has always been with us but we didn't call it that or is it something that has developed more in our modern western kind of society?

Dr. LAZAR. Aldo Alzheimer, for whom the disease is now named, published his work in 1906 and 1907, and that is when it became a part of the literature. There was evidently a 55- or 56-year-old person in an institution who had a lot of behaviors we have been talking about today and had been institutionalized, and he did the brain study on the patient and discovered the tangles, and so forth, and the disease bears his name. It has been identified since the early 20th century.

Mr. MANTON. Has the incidence of it increased?

Dr. MOHS. The epidemiologic studies show that the number of new cases, say, per thousand people in the population, continues to go up until about age 78 or 79, somewhere roughly around there. And so, if you don't have a population where a large number of people live into their 70's and 80's, you won't find very many cases of Alzheimer's disease. That is why, around the turn of the century, the only cases identified were these relatively rare instances where somebody develops the disease, say, in their 50's or 40's. However, we know now the average life expectancy in people in the United States goes up every year, which is a tribute to modern medicine, but what it is doing is enabling lots more people to live into that time of their life when their probability of developing Alzheimer's disease goes up dramatically.

So, it is true that the majority of cases of Alzheimer's disease are found in relatively advanced societies, and it is much more common now than it used to be, but it is not because you couldn't develop it before. It's just that lots more people, because of better cardiovascular care and so forth, live to the age when they are able to develop this disease.

Dr. HELMS. The other thing is obviously that the diagnostic sophistication has changed and has developed. And in fact, what Alzheimer's disease or dementia of the Alzheimer's type is now, used to be called a variety of other things, which in fact have been alluded to today, chronic organic brain syndrome being one, arteriosclerotic brain disease being another. There are many terms which have fallen out of—not entirely out of popularity, but have been cleaned up a bit. We have become much more sophisticated in terms of how to diagnose and what to call and how to differentiate. Particularly, I would like to emphasize in that area, there are many other diseases that look very much like Alzheimer's disease.

As a clinician, the overriding consideration that I have is the early diagnostic assessment of an individual who might have Alzheimer's disease, because of all people who present with dementia, approximately 50 percent do have Alzheimer's disease. But the others have a variety of others, some of which are infinitely treatable. And that is the reason and the importance of early evaluation, early diagnosis. There is no question, we have become much better at that than we were 20 years ago.

Dr. LAZAR. It also used to be believed that there was a presenile dementia and a senile dementia of older age, and as neuropatholo-

gical investigation has increased in sophistication, it has become increasingly believed that it may in fact be variations of the same disorder. Our whole conceptualization of Alzheimer's and what it consists of has changed as techniques have improved.

Mr. MANTON. Mr. Mrazek?

Mr. MRAZEK. Mr. Chairman, I don't have any further questions, but I would like to add my personal appreciation to all of the panelists who testified today, both in the social concern as well as the medical and scientific aspects confronting the issue.

We have been successful for the last 3 years when the administration has attempted to reduce, and at one point eliminate, funding for the 10 research centers. I am confident we will be successful again this year in protecting those centers. But it is clear a great deal more has to be done, and that we are going to have to pursue as aggressively as possible the fund necessary to begin to provide answers in the area of treatment and the caring for families. Families are, in fact, already spending $30,000 a year, as we have heard in testimony, trying to deal with this particular issue without those answers. $12 billion is paid for through Federal taxpayer dollars.

Clearly, with the kinds of progress that has been made, limited at this point but real progress, in those five or six different research areas, and as we expand research in Alzheimer's, hopefully the kinds of answers are going to be provided that, in the long run, are going to reduce the requirement for the commitment of billions of dollars to pick up the pieces of lives that are being destroyed by the disease.

So, I would certainly like to thank you, Dr. Lazar, as one member of the panel, and I very much appreciate your participation, Mr. Chairman, to provide a hearing record which will be presented to the U.S. Congress. Any interested observers of the hearing today who would like to have a copy of the testimony provided in this hearing record, a copy will be made available to you, I am sure, if you contact Congressman Manton's offices, a member of the Select Committee. I can only say that this wasn't necessarily the most pleasant way to spend a Saturday afternoon, but it was certainly a very illuminating one for me, and I am sure for many others in the room today.

Thank you, Mr. Chairman.

Mr. MANTON. Thank you, Mr. Mrazek.

I am very pleased to be here as a member of the Select Committee. I don't know whether at the outset Mr. Downey indicated that we, as a Select Committee, are not a legislative committee or not a legislating committee. What we do is focus on particular problems with our committee, obviously problems of the aging, and we create a record which will be useful for the respective legislative committees to address the issues through authorization and appropriation of the necessary funds to deal with the problems that the Select Committee examines.

I just want to thank my colleague, Bob Mrazek, for being the spearhead, although not a member of the committee itself, of this particular hearing. I think it is important not only here and on Long Island, but we are creating a record for all Americans that will benefit all Americans.

I would like to conclude by saying that in my particular district, the ninth District in Queens, this is particularly relevant since we have an aging population there that is No. 12 out of 435 congressional districts around the country. So I am very pleased to join with Bob Mrazek and Tom Downey today in being with you and having this very, very important hearing.

We thank all of our panalists for giving of their valuable time and spending what is a very pleasant afternoon, dealing with a most important subject.

With that said, we will conclude our hearing and end our testimony for the day.

Thank you.

[Whereupon, at 4:15 p.m., the hearing in the above-entitled matter was closed.]

APPENDIX

LICENSED SPEECH PATHOLOGISTS,
Hauppauge, NY, July 12, 1986.

Hon. ROBERT J. MRAZEK,
House of Representatives,
Roslyn, NY.

DEAR CONGRESSMAN MRAZEK: I wish to express some thoughts on Alzheimer's Disease that you may want to include in your upcoming hearing.

Alzheimer's Disease is a progressive, dementing disease of unknown origin and considered to be the most common degenerative disease of the central nervous system. It presents a significant management problem, predominently due to its concomitant communicative disabilities: inappropriate use of language (pragmatics), diminished cognitive ability, memory dysfunction, and increased lack of emotional control. Often, well-intentioned families, in an effort to protect their loved ones, shield them from situations that reduces their communicational environment and experience, which results in more rapid deterioration.

With improved understanding of the disease, most investigators now believe that Alzheimer's Disease is not a normal consequence of aging. It should also be noted that a pharmaceutical therapeutic program is in the laboratory stage. Dr. Robert E. Harbaugh, Section of Neurosurgery at Dartmouth-Hitchcock Medical Center in mental status, decreased confusion, increased attention and initiative, and improved social interaction, with bethanechol chloride infusion. Dr Harbaugh concludes his report in the *Neurosurgery,* by saying, "we think that this treatment approach may prove to be beneficial for some AD patients and deserves further study."

I would like to offer a list of Helpful Hints in Alzheimer's Management, from a speech-language pathology point of view:

1. Keep the environment as constant as possible;
2. Maintain simple routines;
3. Minimize distractions;
4. Provide memory aids;
5. Provide indirect orientation to time, place and space;
6. Simplify verbal interaction;
7. Provide emotional support;
8. Avoid excessive excitement;
9. Continue communicational stimulation;
10. Provide I.D. bracelet; and
11. Attempt a formal program of communicative therapeutic intervention, especially involving language modalities.

Thank you for interest in Alzheimer's Disease and for the opportunity to express my viewpoint.

Sincerely,

FRANK M. VOLZ, M.S., C.A.,
Speech-Language Pathologist.

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